

AWARD NUMBER: W81XWH-12-1-0553

TITLE: Systematic Assessment of Caregiving Skill Performance by Individuals with Tetraplegia and Their Caregivers

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REPORT DATE: December-2017

TYPE OF REPORT: Final

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
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REPORT DOCUMENTATION PAGE				Form Approved OMB No. 0704-0188	
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1. REPORT DATE Dec-2017		2. REPORT TYPE Final		3. DATES COVERED 30-Sep-2012 to 29-Sep-2017	
4. TITLE AND SUBTITLE Systematic Assessment of Caregiving Skill Performance by Individuals with Tetraplegia and Their Caregivers				5a. CONTRACT NUMBER	
				5b. GRANT NUMBER W81XWH-12-1-0553	
				5c. PROGRAM ELEMENT NUMBER	
6. AUTHOR(S) Jeanne M. Zanca, PhD,MPT E-Mail: jzanca@kesslerfoundation.org				5d. PROJECT NUMBER	
				5e. TASK NUMBER	
				5f. WORK UNIT NUMBER	
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Kessler Foundation 120 Eagle Rock Avenue East Hanover, NJ 07936-3147				8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012				10. SPONSOR/MONITOR'S ACRONYM(S)	
				11. SPONSOR/MONITOR'S REPORT NUMBER(S)	
12. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited					
13. SUPPLEMENTARY NOTES					
14. ABSTRACT This study has increased our understanding of the direction-of-care/caregiving training process and created an assessment tool to assist clinicians in identifying training needs and describing progress as people with tetraplegia (PWT) and their caregivers learn direction of care/caregiving skills. Stakeholders (people with tetraplegia, caregivers, clinicians) identified a number of daily activities in which PWT work with caregivers, and identified safely of task performance, problem-solving ability, and communication skills as key indicators of skill in directing and providing care. An assessment tool ("Teaching Effective Assistance Management" or "TEAM" Tool) and accompanying instruction guide have been created and pilot-tested. This work will contribute to the process of enabling people with tetraplegia to live healthy and successful lives in the community.					
15. SUBJECT TERMS Rehabilitation, spinal cord injury, assessment, qualitative research, caregiving					
16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT Unclassified	18. NUMBER OF PAGES 159	19a. NAME OF RESPONSIBLE PERSON USAMRMC
a. REPORT Unclassified	b. ABSTRACT Unclassified	c. THIS PAGE Unclassified			19b. TELEPHONE NUMBER (include area code)

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1. INTRODUCTION

The objective of this study was to create an assessment tool for use by clinicians during inpatient rehabilitation to systematically evaluate and describe self-direction of care and caregiving skills. These sets of skills are unaddressed by functional outcome measures currently used in inpatient care and rehabilitation research. As a result, current measures are inadequate to describe progress made during inpatient rehabilitation by people with tetraplegia (PWTs), for whom **training** in self-direction of care and family training in caregiving skills are important areas of rehabilitation intervention. (Note that “caregiving” and “self-care” refer broadly to the performance of basic and advanced activities of daily living (ADLs), medical treatments such as suctioning, mobility, maintenance of a healthy living environment, and all other tasks needed to maintain health, well-being, and productivity for PWTs.) This project addressed this gap in assessment by creating a tool specifically designed to assess self-direction of care and caregiving skills. The project had four specific aims: (1) Identify rehabilitation goals related to self-direction of care and caregiver performance of care tasks, indicators of progress toward those goals, and criteria for establishing competency that are meaningful to SCI clinicians, PWTs, and their caregivers. (2) Create an assessment tool that reflects these goals, indicators, and criteria. (3) Assess the comprehensiveness and utility of the tool in inpatient rehabilitation qualitatively, by piloting its use in that setting and obtaining feedback from end-users. (4) Based on this feedback, create a refined version of the assessment tool suitable for further development and evaluation in subsequent research.

2. KEYWORDS

Rehabilitation, spinal cord injury, assessment, qualitative research, caregiving

3. ACCOMPLISHMENTS

As described in the Statement of Work, project activities were divided into three phases. The response to each question is subdivided by Phase.

What were the major goals of the project?

Phase I – Content Identification

Goal 1: Review the inpatient rehabilitation charts of up to 10 people with tetraplegia (PWTs) to learn more about goals for direction of care/caregiver training, indicators of progress, and criteria for establishing competency.

Goal 2: Conduct focus groups with PWTs with experience directing their care, caregivers, and SCI clinicians to gain a better understanding of the process of learning direction of care and caregiving skills and to obtain suggestions for the content and format of the assessment tool.

Phase II – Creation of Draft Assessment Tool

Goal: Create an assessment tool that reflects the input of key stakeholders in Phase I with respect to the kinds of direction of care/caregiving skills that are important to assess, how they should be evaluated, and how the tool should be used in rehabilitation.

Phase III – Piloting

Goal 1: Obtain feedback on the comprehensiveness and utility of the tool from target end-users of the tool (inpatient rehabilitation clinicians and those being assessed).

Goal 2: Create a refined version of the assessment tool suitable for further development and evaluation in subsequent research.

What was accomplished under these goals?

Phase I – Content Identification

1) Major Activities

Two major activities took place in Phase I: reviews of inpatient charts of PWTs who received rehabilitation at Kessler, and focus groups with PWTs, caregivers, and SCI professionals.

Chart reviews were conducted for eight participants who were admitted to Kessler for inpatient rehabilitation for acute spinal cord injury. A data abstraction guide was developed to provide detailed information about the types of patient/caregiver-clinician interaction documentation that should be abstracted and give guidance on the mechanics of abstraction (replacement of proper names for patients and caregivers with "patient" or "patient's wife," for example). The guide served as a means of documenting decisions made during data abstraction and provided clear instructions to the team so that data were collected in a consistent manner. The guide was updated on an ongoing basis as questions arose. Abstracted data were analyzed to identify topics of direction of care/caregiving skill training, instructional techniques, and methods for assessing and describing skill level.

Focus groups were conducted at each of the three participating centers (Kessler, Shepherd Center, East Orange VA - EOVA). Separate groups were held for PWTs with chronic SCI, caregivers of PWTs with chronic SCI, and SCI professionals (9 groups total). See Table 1 for the number of participants in each focus group at each site and Appendix 2 for characteristics of focus group participants. Each focus group was approximately 3 hours in duration (30 minutes administrative time and 2.5 hours for group discussions). All groups were facilitated by the lead investigator (Zanca). Focus groups typically took place in-person, but conference calls were utilized at the East Orange VA site to facilitate participation of caregivers who had difficulty traveling to campus due to their caregiving responsibilities. Discussion topics included experiences learning (or teaching, in the case of clinicians) direction of care and caregiving skills, goals considered important to address in inpatient rehabilitation in preparation for return

home, indicators of good quality direction of care or caregiving, and desired characteristics of an assessment tool (see Appendix 3 for copies of the question guides for the focus groups). Open discussions were held and new questions were raised by the facilitator as needed to clarify statements from participants or to explore new topics or issues raised by participants. Focus group discussions were recorded digitally and transcribed by a professional transcription company. Transcripts were reviewed by the facilitator for accuracy and completeness and were imported into NVivo software to facilitate qualitative analysis. Transcripts were read by all analysts (Zanca, Morris, Dijkers). A first round of coding of emerging themes was performed by Dr. Zanca and reviewed by Dr. Morris who suggested additions and revisions to the themes identified. A final version of themes was determined by consensus of Dr. Zanca, Morris, and Dijkers and was used to inform development of the assessment tool in Phase II.. Additional analysis were done of themes related to interpersonal relationships and barriers and facilitators to learning to direct one's own care.

Table 1. Number of Focus Group Participants Enrolled by Site and Constituency

	Kessler	Shepherd Center	EOVA	<i>Total by Constituency</i>
People with Chronic Tetraplegia	9	8	9	26
Caregivers of People with Chronic Tetraplegia	4	7	5	16
SCI Professionals	9	9	7	25
<i>Total by Site</i>	22	24	21	67

2) *Specific Objectives*

The objective of Phase I was to inform the content and format of the assessment tool by obtaining input from key stakeholders (PWTs, caregivers, and SCI clinicians) about the kinds of skills that are needed for successful direction of care and caregiving, indicators of skill level, and the dynamics under which the tool would be used.

3) *Significant Results or Key Outcomes*

Chart Review:

The people who receive caregiver education during the inpatient rehabilitation stay are varied, including spouses, children, parents, and friends of the person with tetraplegia, as well as home health aides or personal care attendants who may be hired by the person with tetraplegia to facilitate his/her return to home. Instructional methods include discussion and verbal presentation of information, provision of written materials, demonstration of skills, and opportunities to practice skills with feedback from clinicians. A wide variety of topics related to self-care, activities of daily living, equipment use, secondary complications, emergency preparedness, and medical issues appeared in clinical documentation of patient and caregiver training (see Table 2).

Table 2. Themes for Topics and Subtopics of Direction of Care and/or Caregiver Training

<i>Main Topic</i>	<i>Subtopics</i>
Activities of Daily Living (ADLs)	Bathing (in bed, in shower chair) Dressing upper and lower body Bed mobility Transfers (to bed, shower chair, etc.) Bowel and bladder care Electronic ADLs (setup of a tablet computer or cell phone for use by person with tetraplegia, for example)
Durable Medical Equipment (Features and Use)	Shower/commode chair Mechanical lift (sling setup, operation to perform transfer) Manual wheelchair (use of manual tilt-in-space, wheel locks, traversing curbs/ramps, etc.) Power wheelchair (use on wheelchair lift, attendant drive, etc.) Hospital bed Rotating mattress Positioning devices (such as resting hand splint, wheelchair seating components)
Management and Prevention of Secondary Complications	Pain management techniques Skin integrity preservation (skin inspection, skin care, weight-shifting, positioning, etc.) Passive range of motion Autonomic dysreflexia (signs, symptoms, interventions) Orthostatic hypotension (signs, symptoms, interventions) Respiratory care (swallowing techniques to avoid aspiration, assisted cough, etc.)
Emergency Preparedness	Emergency ventilation (using manual bag technique) Evacuation methods (chair bumping, two person lift)
Other Medical Issues	Breathing (ventilator use, supplemental oxygen use, etc.) Medication management

Clinicians use several techniques to assess the ability of people with tetraplegia and their caregivers to direct care or perform care tasks. These include: (1) “quizzing” patients or caregivers orally to assess knowledge relevant to task performance; (2) asking patients or caregivers to demonstrate (verbally or physically as applicable) how they would instruct or perform a task; and (3) observing their behavior (without specifically asking for a skill to be demonstrated) to assess the extent to which they have integrated tasks into their daily routine (such as requesting a weight-shift from a caregiver at a specified interval).

A variety of descriptors are used to characterize the ability of people with tetraplegia and/or their caregivers to direct or perform care tasks (see Table 3). These descriptors appear in goals

(particularly short-term goals) set by the clinical team and in progress notes.

Table 3. Themes and Examples of Descriptors of Direction of Care/Caregiving Skill Performance Ability

<i>Descriptor</i>	<i>Examples (Quotations from Medical Record)</i>
Level of independence (includes need for verbal cueing)	<p>“Patient’s spouse required moderate verbal cues for technique, minimal verbal cues for safety, and moderate assistance with use of mechanical lift.”</p> <p>“Patient requested to be re-positioned in manual recliner wheelchair. Therapist asked for patient to instruct him on appropriate/safe handling techniques to assist with his request. Pt able to complete with minimal verbal cues.”</p> <p>“Patient demonstrated independence in instruction of others for completion of activities of daily living, bed positioning and functional transfers ...”</p>
Quality of demonstration of a task	“Demonstrated task with good return/successful demonstration.”
Accuracy of task performance or knowledge demonstration	<p>“Patient able to recall weight shift protocol with 100% accuracy.”</p> <p>“Patient will instruct home health aide on set up of sling and patient lift in preparation to perform mechanical lift transfer to/from shower commode chair and bed with 100% accuracy.”</p>
Timing of task performance	“Patient will initiate at least one weight shift at appropriate intervals...”
Frequency with which task is performed correctly	“Patient will instruct others with set up of mechanical sling with 100% accuracy 2/5 treatment sessions.”
Completeness of knowledge verbalized upon request	“Patient will verbalize 50% of bony prominences most prone to skin breakdown without verbal cues from this therapist.”
Need for further training	“Requires further training.”

Focus Groups:

The focus groups were very informative, providing both general information on the process of learning to direct or provide care, and specific suggestions for the content and scoring of the assessment tool. See Appendix 4 for a summary of themes and their implications for assessment

tool development. Key themes that emerged from the focus groups that were later used to guide development of the assessment tool included:

- The types of tasks with which assistance is needed are varied and encompass nearly all aspects of life (not just medical care). (See Appendix 5 for a comprehensive listing of tasks with which assistance is needed as well as other skills considered important for care direction or caregiving.)
- Each person with tetraplegia has specific needs and preferences for how things are done
- Tasks that could cause medical complications if not done properly were generally considered most important
- Successful direction of care requires:
 - Self-awareness and understanding of your body
 - Ability to communicate your needs clearly and specifically
 - Confidence to self-advocate
 - Problem-solving ability
 - Patience and flexibility (to a point)
- Teamwork is critical; interpersonal skills are important for both care directors and caregivers
- Many factors make direction of care/caregiving skill training challenging during inpatient rehabilitation:
 - Denial of injury and functional status
 - Shrinking lengths of stay
 - Being overwhelmed
 - Difficulty scheduling training with caregivers
 - Lack of physical or emotional readiness among caregivers
 - Differences between rehab and “the real world”
 - Most people with tetraplegia/caregivers reported that experience, trial-and-error were greatest teachers
- Understanding why a particular task needs to be done a certain way is critical to:
 - Engage people who are being trained to direct or provide care
 - Facilitate positive interpersonal dynamics (by giving credibility to the person with tetraplegia and respect to the caregiver’s contribution)
 - Problem-solve
- Clinicians reported several possible ways in which an assessment tool for direction of care/caregiving skills could be helpful:
 - Setting goals
 - Building confidence
 - Promoting conversations about difficult subjects (ability to provide care, willingness, interpersonal dynamics)
 - Planning for discharge (assessing readiness, identifying areas to cover to prepare, etc.

Two presentations were given to discuss the subset of themes relevant to establishing positive working relationships between caregivers and PWTs and barriers and facilitators to learning to direct one’s care. See Appendix 6 for copies of the abstracts and Appendix 7 for the full versions of these presentations, which provide greater depth on findings related to these themes.

4) Other Achievements

A newsletter article for people with SCI and their loved ones was published to share the suggestions offered for fostering positive working relationships between caregivers and PWTs (Appendix 8). The circulation of Kessler's *Connections* newsletter is greater than 1,000, with additional copies downloaded online.

The focus groups provided preliminary data to support a successful grant application to fund the creation of a web-based "Introduction to SCI" Course for personal care assistants. (See Section 4 for more details.)

Phase II – Creation of Tool

1) Major Activities

Using the themes identified in Phase I, a draft of the assessment tool and instruction guide was created. The tool was named the TEAM Tool (TEAM = "Teaching Effective Assistance Management") to emphasize the importance of collaboration and interpersonal interaction to the success of direction of care and caregiving. Key features of the draft of the tool included:

- Three parts (A, B, C) that list tasks with which help may be needed from caregivers
 - **Part A:** Health and/or everyday functioning ("meat and potatoes" of inpatient rehab)
 - **Part B:** Communication-related behaviors
 - **Part C:** Home and community skills, as well as managing hired staff, if applicable (some tasks here may not be addressed until later in rehabilitation process)
- Separate scoring for Care Director, Caregiver, and Team
 - Reflects that each member contributes in his/her own way and that the team has a synergy
 - Provides flexibility in cases where a caregiver is not available for assessment
- Three scales for scoring, each describing different aspects of task performance:
 - Safety (Parts A and C)
 - Problem-Solving (Parts A and C)
 - Communication (Part B only)
- Scores reflect ability to appropriately execute that aspect of task performance *without assistance from the trainer*
- Scores based on performance observed during week preceding tool completion date (allows greater opportunity to observe behavior than would be the case if assessment focused on observations made in a single day or session)

Once a version of the TEAM Tool was created with input from investigators, the TEAM Tool was shared with participants in the Phase I focus groups to obtain feedback. A series of 6 conference calls involving 14 participants (4 people with tetraplegia, 2 caregivers, 8 clinicians) were conducted. After each call, adjustments were made to the tool so that feedback on the revised version could be given in subsequent calls. Adjustments were made to the list of tasks to

address tasks that were perceived to be missing or needed greater emphasis. Revisions were also made to the scoring system, bringing it from a 6-point system to a 4-point system. This change was recommended by call participants to simplify the process of scoring and align with how clinicians typically think of skill level. The versions of the TEAM Tool and instruction guide that were used for piloting are presented in Appendix 9 and 10 to this report.

2) Specific Objectives

The objectives of Phase II were to create an assessment tool for direction of care/caregiving skills that reflected the priorities and perspectives of key stakeholders (PWTs, caregivers, SCI professionals).

3) Significant Results

Copies of the instruction guide and TEAM Tool that were prepared for piloting appear in Appendix 9 and 10.

4) Other Achievements

Nothing to Report

Phase III – Piloting of Assessment Tool

1) Major Activities

Piloting took place at Kessler and Shepherd Center. As shown in Table 4, a total of 42 clinicians were trained in the use of the TEAM Tool. Training was delivered by Dr. Zanca and was given either in-person or via web-based video conference using Go-To-Meeting. Rather than giving one large training session at each site, several smaller trainings were offered and helped increase the number of participating staff, especially for nurses whose schedules vary widely from week to week.

The TEAM Tool was pilot-tested with 48 PWTs who enrolled in the study and 31 caregivers associated with those PWTs. (The number of caregivers is less than the number of PWTs because some PWTs had no family or others who could participate in training during the rehabilitation stay.) Because there is often overlap in disciplines in certain areas of training (PT and OT on positioning, nursing and OT on bladder management, for example) all clinicians who were enrolled in piloting and worked with an eligible patient were instructed to score the TEAM Tool, leaving blank any items that fell outside their scope of practice. Clinicians were instructed to complete the TEAM Tool once in three different periods: once in the first two weeks of admission, once in the middle two weeks of the stay (as best as could be calculated based on planned discharge date) and once in the two weeks before discharge.

Clinicians provided written comments on the TEAM Tool forms themselves, via email communications with study coordinators at each site, and in focus groups facilitated by Dr. Zanca and held at each piloting center. Focus groups with staff involved in piloting took place

approximately half way through data collection at each site, and provided an opportunity to discuss data collection status, address questions about instructions for completion, and obtain preliminary feedback on the tool. A second set of groups took place at the conclusion of data collection.

Table 4. Number of Participants Enrolled in Phase III (Piloting)

Participant Type	Shepherd	Kessler	TOTAL
Clinicians	19	23	42
<i>Physical Therapists</i>	7	6	13
<i>Occupational Therapists</i>	8	7	15
<i>Nurses*</i>	3	9	12
<i>Speech Therapists</i>	1	0	1
<i>Case Managers</i>	0	1	1
People with Tetraplegia	35	13	48
Caregivers	21	8	29
TOTAL for all Participant Types	77	44	121

* 3 enrolled nurses were withdrawn because they transferred to another facility or unit.

Interviews were also conducted via conference call with participants at Shepherd Center (3 PWTs, 3 caregivers) and Kessler (3 PWTs, 4 caregivers) after discharge from inpatient rehabilitation. The TEAM Tool was reviewed with them during these conference calls, and feedback on its content and proposed use was sought.

2) *Specific Objectives*

The objectives of Phase III were to obtain feedback on the TEAM Tool to guide its revision and create a version suitable for further development and evaluation in subsequent research.

3) *Significant Results*

See Appendix 11 for a summary of feedback obtained from clinicians.

Clinicians generally found the TEAM Tool to be comprehensive, including all the tasks considered important for maintaining health and maximizing function. While providing separate sets of scores for the Care Director, Caregiver, and Team did increase the time required to complete the tool, clinicians felt there it was informative to have three sets of scores, and felt that this feature should be retained. Suggested revisions to content and format included:

- 1) Creating an electronic version of the form in which descriptions of each task can be accessed by clicking on the task to reduce the need to refer back to the instructions and generally speed up the completion process.

- 2) Merging tasks (or communication skills for Part B) that are similar or very closely-related (transfers on level vs. uneven surfaces, for example) to reduce burden of completion.
- 3) Emphasizing the importance of certain tasks (such as weight-shifting) by listing them separately rather than embedding them in other tasks.

Scoring of both safety and problem-solving for every task was considered burdensome by some, but there was not clear agreement about how best to resolve the issue, as both safety and problem-solving were considered important to describe. Further development work is planned, and this issue will be addressed in that process.

With respect to the dynamics of its use, we observed that it was often difficult for clinicians to complete all three assessments due to staff vacation schedules, competing demands on staff time, or lack of availability of the PWTs due to transfers to acute care due to complications. Clinicians offered several suggestions for addressing this issue in the future, including the above-mentioned changes to reduce burden (electronic form, combining related tasks) as well as dividing responsibility for TEAM tool completion among members of the rehabilitation team. They also found the admission assessment (done within the first two weeks of admission) to be of little use as most tasks received very low scores (typically 1). Instead, they suggested that the tool be reviewed (but not scored) with PWTs and caregivers early in their admission to introduce them to what they will be learning, and that the first scoring should be done further into the stay and at regular intervals thereafter.

PWTs who were recently discharged from rehabilitation and their caregivers also expressed that the TEAM Tool was comprehensive and that it capture information they felt was relevant to successful direction of care and caregiving in the community. They supported the suggestion made by clinicians to review the TEAM Tool without scoring it early in the stay to orient those being trained. They also felt that some opportunity for self-assessment would be useful to be able to identify areas in need of further training and increase likelihood of being prepared for home.

The revised versions of the TEAM Tool and instruction guide appear in Appendix 12 and 13.

4) Other Achievements

Nothing to Report

Discussion of Stated Goals Not Met. Enrollment for PWTs was stopped just 2 participants short of the target of 50 to provide adequate time for discharge assessments to be completed prior to the end of the study. Similarly, fewer than 10 PWTs and caregivers at each site were interviewed due to the timing of their discharge relative to the end of the grant period and/or their demanding schedules.

What opportunities for training and professional development has the project provided?

Nothing to Report

How were the results disseminated to communities of interest?

Four presentations have been made of this work at professional conferences, including the Academy of Spinal Cord Injury Professionals (ASCIP) Educational Conference and Expo and the American Congress of Rehabilitation Medicine Annual Meeting (ACRM). ASCIP is attended by SCI professionals (therapists, social workers, case managers, nurses, physicians) involved in direct patient care, supervisors and managers of clinical programs, and researchers. ACRM is attended by rehabilitation researchers and clinicians in all disciplines who work with a variety of disability types. Audience members for these presentations provided considerable positive feedback, reinforcing the importance of direction of care and caregiving skills for successful community living and expressing that the TEAM Tool would provide important information to assist the training process.

1. Zanca JM. Direction of Care and Caregiver Training in Inpatient Rehabilitation. Poster presented at the Academy of Spinal Cord Injury Professionals Educational Conference and Expo; 2015 Sep 6-9; New Orleans, LA.
2. Zanca JM, Morris J, Gibson-Gill C, Dijkers, M. Building Positive Working Relationships Between People with SCI and Caregivers. Oral presentation given at the Academy of Spinal Cord Injury Professionals Educational Conference and Expo; 2016 Sep 4-7; Nashville, TN.
3. Zanca JM, Morris J, Gibson-Gill C, Dijkers, M. Learning to Direct Care After Spinal Cord Injury. Poster presented at the American Congress of Rehabilitation Medicine Annual Meeting; 2016 Nov 2-4; Chicago, IL.
4. Zanca JM, Morris J, Gibson-Gill C, Dijkers M. Development of the TEAM Tool: An Assessment of Skills in Directing Care and Caregiving. Poster presented at the American Congress of Rehabilitation Medicine Annual Meeting; 2017 Oct 25-28; Atlanta, GA.

In addition to these presentations, a newsletter article targeted to people with SCI and their families was published which shared suggestions for fostering positive relationships between people with SCI and their caregivers (see Appendix 8). Additional newsletter articles and social media posts sharing insights from the project are planned in the future.

What do you plan to do during the next reporting period to accomplish the goals?

Nothing to Report (Final Report)

4. IMPACT

What was the impact on the development of the principal discipline(s) of the project?

Impacts from this project come from the TEAM Tool itself and from the rich data set created through the focus groups conducted for this project.

- The TEAM Tool will improve communication about direction of care and caregiving skills, leading to better preparation of PWTs and caregivers for a successful discharge to the community.*** The TEAM Tool is anticipated to help the process of training caregivers and people with SCI in several ways. First, it provides a comprehensive listing of areas in which training is needed, which helps clinicians ensure all important topics are covered and helps orient those being trained to the kinds of tasks they will work on together to prepare for discharge. Second, the tool will facilitate identification of training goals by drawing attention to areas in need of further training to achieve safety or improve problem-solving ability. Third, the TEAM Tool will help to facilitate communications among members of the therapy team on training status as well as communications between clinicians and those being trained about current skill level and readiness for discharge. Finally, the TEAM Tool may assist the process of communicating with third party payers to help justify increased time in rehabilitation for training.
- Insights about the direction of care/caregiving training process obtained from this study will inform efforts to develop programs and services to prepare PWTs and caregivers for successful transition to the community.*** Data gathered in the focus groups have led to a greater understanding of the direction of care/caregiving training process, including its contents and barriers and facilitators to its success. Focus group participants spoke about the challenges of adjusting to injury and the overwhelming nature of acute rehabilitation immediately following injury. These data will be valuable to leaders of rehabilitation programs at the participating facilities and beyond to assist their quality improvement efforts and assist them in refining the design of training programs to better accommodate the needs of people with SCI and their families. Insights gained from the project are currently being used to assist Kessler Institute for Rehabilitation as it re-designs its SCI education program for people with SCI and family members.
- Advice shared by PWTs and caregivers provides content for future educational materials.*** People with tetraplegia and their caregivers offered a number of practical suggestions that would be useful to people who are newly injured and their loved ones. These included tips for interviewing personal care attendants, suggestions for how to communicate successfully with caregivers, key signs of potential medical complications, strategies to avoid errors in care (keeping lists, organizing supplies, etc.), among others. This information may form the basis of training materials and programs to help people who are newly injured and their loved ones be better prepared to direct and/or provide care after discharge.
- Data from this project led to the design and funding of a new project to develop a web-based “Introduction to Spinal Cord Injury” course targeted to personal care assistants.*** This project was inspired by findings from the focus groups conducted prior to TEAM Tool development, in which frequent turnover of personal care assistants and the need to orient them to the needs of people with SCI were discussed by many participants. Data from the project were used to support a grant application to the National Institute on Disability and Rehabilitation Research for a project entitled “Improving Quality of

Personal Care Assistance Services for People with SCI Through Online Education.” Objective of the project are to: 1) Identify learning needs of personal care assistants (PCAs) through focus groups with key stakeholders, including people with spinal cord injury (SCI) and their families, PCAs, SCI clinicians, and care agency representatives; 2) Create a course curriculum and web-based materials to implement that curriculum; 3) Pilot-test the online course with personal care assistants who are unfamiliar with SCI to create a final version that is suitable for use by the public. Details about this grant award are as follows:

Title: Improving Quality of Personal Care Assistance Services for People with SCI through Online Education

Agency: National Institute on Disability and Rehabilitation Research

Grant Number: 90IF0115-01-00

PI: Jeanne M. Zanca, PhD, MPT

Role: Co-Investigator

FTE: 20% (Years 1 and 3). 25% (Year 2)

Period: 9/30/2016 – 9/29/2019

Total award: \$ 595,724

- ***The current version of the TEAM Tool will form the basis for future versions suitable for use in clinical research to demonstrate linkages between care skills, secondary complications, and quality of life.*** In its present form, the TEAM Tool is anticipated to be most useful as means of improving communication and care delivery processes. As stated in the original grant, additional development work will be needed to examine the quantitative properties of the TEAM Tool and create a version suitable for use in outcomes measurement in clinical research. The current version of the team tool lays a foundation for future development work, including work to develop new tools with potential value, such as a self-assessment of direction of care and caregiving skills.

What was the impact on other disciplines?

Nothing to Report

What was the impact on technology transfer?

Nothing to Report

What was the impact on society beyond science and technology?

Nothing to Report

5. CHANGES/PROBLEMS

Nothing to Report (Changes/problems have been reported in writing in previous reports.)

6. PRODUCTS

Publications, conference papers, and presentations

1. Zanca JM. Direction of Care and Caregiver Training in Inpatient Rehabilitation. Poster presented at the Academy of Spinal Cord Injury Professionals Educational Conference and Expo; 2015 Sep 6-9; New Orleans, LA.
2. Zanca JM, Morris J, Gibson-Gill C, Dijkers, M. Building Positive Working Relationships Between People with SCI and Caregivers. Oral presentation given at the Academy of Spinal Cord Injury Professionals Educational Conference and Expo; 2016 Sep 4-7; Nashville, TN.
3. Zanca JM, Morris J, Gibson-Gill C, Dijkers, M. Learning to Direct Care After Spinal Cord Injury. Poster presented at the American Congress of Rehabilitation Medicine Annual Meeting; 2016 Nov 2-4; Chicago, IL.
4. Zanca JM, Morris J, Gibson-Gill C, Dijkers M. Development of the TEAM Tool: An Assessment of Skills in Directing Care and Caregiving. Poster presented at the American Congress of Rehabilitation Medicine Annual Meeting; 2017 Oct 25-28; Atlanta, GA.

Journal publications

Nothing to report (manuscripts are in preparation)

Books or other non-periodical, one-time publications

Nothing to Report

Other publications, conference papers, and presentations

A newsletter articles that summarizes advice on building positive working relationships with caregivers has been published (see Appendix 8).

Website(s) or other Internet site(s)

Nothing to Report

Technologies or techniques

Nothing to Report

Inventions, patent applications, and/or licenses

Nothing to Report

Other Products

1. Teaching Effective Assistance Management (TEAM) Tool

The TEAM Tool provides a mechanism for clinicians to systematically evaluate the ability of people with tetraplegia to direct their care and the ability of caregivers to provide appropriate assistance. The tool is currently being pilot-tested in inpatient rehabilitation.

2. TEAM Tool Instruction Guide

The instruction guide describes the purpose and intended use of the TEAM Tool, and provides definitions for terms used in the tool. The guide is used to train clinicians in the use of the tool and to serve as an ongoing reference during piloting.

Copies of the TEAM Tool and instruction guide are available upon request of Dr. Zanca. Plans are underway to seek funding to create an electronic version of the tool to be made widely available at no cost to users.

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Kessler Foundation

Jeanne Zanca – No Change

Name:	Kehinde Cole
Project Role:	Research Assistant
Nearest Person-Month Worked:	6
Contribution to Project:	<ul style="list-style-type: none">▪ Recruited participants for piloting at Kessler and obtained informed consent▪ Assisted with logistical arrangements for clinician training (room reservations, refreshments, subject compensation, etc.) and piloting▪ Assisted with IRB applications▪ Maintained study documentation

Shepherd Center

John Morris – No Change

Marina Moldavskiy – No Change

Mount Sinai (Later Unaffiliated)

Marcel Dijkers – No Change

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?

Nothing to Report

What other organizations were involved as partners?

Organization Name:	East Orange Campus of the VA New Jersey Health Care System
Location of Organization:	East Orange, NJ
Partner's contribution to the project:	Collaboration (e.g., partner's staff work with project staff on the project)

Organization Name:	Icahn School of Medicine at Mount Sinai
Location of Organization:	New York, NY
Partner's contribution to the project:	Collaboration (e.g., partner's staff work with project staff on the project)

Organization Name:	Shepherd Center
Location of Organization:	Atlanta, GA
Partner's contribution to the project:	Collaboration (e.g., partner's staff work with project staff on the project)

8. SPECIAL REPORTING REQUIREMENTS

Not Applicable

9. APPENDICES

The following appendices are included with this report:

- (1) Updated Quad Chart
- (2) Characteristics of Phase I Focus Group Participants
- (3) Focus Group Question Guides
- (4) Themes and Implications for Assessment Tool Development
- (5) Master List of Tasks/Knowledge Areas for People with Tetraplegia and/or their Caregivers
- (6) Presentation Abstracts
- (7) Full Presentations (Oral and Poster)
- (8) Newsletter Article
- (9) TEAM Tool – Version for Piloting
- (10) TEAM Tool Instruction Guide – Version for Piloting
- (11) Team Tool Clinician Debriefings – Summary of Feedback
- (12) TEAM Tool – Revised Version
- (13) TEAM Tool Instruction Guide – Revised Version

APPENDICES

Systematic Assessment of Caregiving Skill Performance by Individuals with Tetraplegia and Their Caregivers

Log #: SC110247 Award # W81XWH-12-1-0553

PI: Jeanne M. Zanca, PhD, MPT Org: Kessler Foundation (after transfer from Mount Sinai School of Medicine) Award Amount: \$618,139



Study/Product Aim(s)

- (1) Identify care-direction and caregiving skills and criteria for evaluating those skills that are meaningful to SCI clinicians, people with tetraplegia (PWTs), and their caregivers.
- (2) Create an assessment tool that reflects these goals/indicators/criteria.
- (3) Assess the comprehensiveness and utility of the tool in inpatient rehabilitation.
- (4) Create a refined version of the assessment tool suitable for further development and evaluation in subsequent research.

Approach

Chart reviews and focus groups will be used to identify relevant content for the assessment tool; the tool will be drafted with feedback from PWTs, caregivers, and clinicians; pilot-testing in rehabilitation will be done to refine the assessment tool for further testing in future studies

Improved assessment of skills over time

Better planning and evaluation of training

Improved skill acquisition by PWTs and caregivers

Fewer complications and better quality of life

Figure: Projected impacts of project on people with tetraplegia and their caregivers. Accomplishment: 8 chart review, 67 focus group, and 121 piloting participants enrolled; four scientific presentations; 161 TEAM Tool assessments completed

Timeline* and Cost

Activities	FY 14	FY 15	FY 16-17
Identify relevant content for instrument via chart review, focus groups, interviews			
Create initial version of assessment instrument			
Pilot-test the instrument in inpatient rehabilitation			
Estimated Budget (\$618,139)	236,124	173,884	208,131

Goals/Milestones

Focus groups complete; "Teaching Effective Assistance Management [TEAM] Tool"/instructions created; four scientific presentations; 121 piloting participants enrolled (including 42 clinicians trained in use of tool); 161 TEAM Tool assessments completed; Feedback from clinicians, PWTs caregivers obtained, TEAM Tool revised

Future Goals

- Continue dissemination of project findings and TEAM Tool through papers and presentations to clinicians, consumers, researchers
- Seek other funding to create electronic version of tool
- Current TEAM Tool suited for use in team communication and process improvement; Conduct additional development work to assess utility for outcomes measurement in clinical research

Comments/Challenges/Issues/Concerns

- Fewer than budgeted funds expended due to circumstances including final number of enrolled participants, staff vacancies

Budget Expenditure

Projected Expenditure: >\$618,000 Actual Expenditure: \$593,783

Updated: 29-Dec-2017

* EWOFF request approved

APPENDIX 2

Characteristics of Focus Group Participants

Table A1. Participant Characteristics for Focus Group Participants with Tetraplegia

	Kessler	Shepherd	East Orange VA
n	9	8	9
Age in Years [Median (Range)]	44 (29–67)	45 (30-61)	59 (43-81)
Sex [% Male]	67	57	100
Ethnicity [%Hispanic]	11	0	11
Race [% Caucasian]	56	57	33
Years Post-Injury [Median (Range)]	16 (2-50)	20 (1-44)	21 (2-38)
Paid Hours of Care Received Per Week [Median (Range)]	37 (6-56)	35 (9-72)	36 (0-140)
Unpaid Hours of Care Received Per Week [Median (Range)]	10 (2-12)	12 (0-24)	24 (2-168)

Table A2. Characteristics of Caregiver Focus Group Participants

	Kessler	Shepherd	East Orange VA
n	4	7	5
Age in Years [Median (Range)]	61 (24–70)	52 (43-61)	63 (24-74)
Sex [% Male]	25	14	20
Ethnicity [%Hispanic]	25	0	0
Race [% Caucasian]	50	14	60
Years of Experience Providing Care [Median (Range)]	15 (3-25)	15 (1-35)	4 (2-38)
Hours of Care/Week Provided [Median (Range)]	30 (8-100)	48 (4-120)	40 (10-168)
% Hired (vs. Informal)	25	71	0

Table A3. Characteristics of Clinician Focus Group Participants

	Kessler	Shepherd	East Orange VA
n	9	9	7
Age in Years [Median (Range)]	39 (28-59)	41 (25-46)	41 (35-53)
Sex [% Male]	0	22	17
Ethnicity [%Hispanic]	0	0	0
Race [% Caucasian]	89	89	17
Discipline [%]			
Nursing	22	33	33
Occupational Therapy	33	33	17
Physical Therapy	33	33	17
Other	11	0	33
Years SCI Rehab Experience [Median (Range)]	12 (4-37)	8 (3-13)	10 (7-21)

APPENDIX 3

Focus Group Question Guides

Systematic Assessment of Caregiving Skill Performance by Individuals with Tetraplegia and Their Caregivers – IRB # E-772-13

Focus Group Questions for People with Tetraplegia – MASTER QUESTION LIST for Study Team

VERIFY RECORDERS ARE TURNED ON BEFORE STARTING DISCUSSION

- 1) The first thing we will talk about together is “directing your care.” By that I mean the process of telling caregivers what you need to have done and giving them instructions about how to assist you. How did you learn to direct your care?
 - a) Who taught you?
 - b) How did they teach you?
 - c) When did that teaching happen?
 - d) Was the teaching you received clear? How much did you have to improvise or try-and-fail once you actually started directing your care?
 - e) How much did you learn about directing your care through formal training (by rehab professionals) versus trial-and-error or other means? What other things (besides formal training) helped you learn to direct your care?
 - f) Did you and/or your caregivers receive training in inpatient rehabilitation? If so, what was taught? What could the rehab team have done differently during inpatient rehab to better prepare you and/or your caregivers?
 - g) *[Skip if time concerns]*How was feedback given while you were learning to direct your care?
 - h) *[Skip if time concerns]* What kinds of feedback were most helpful?

- 2) To direct care well, there are things that people with tetraplegia need to KNOW (information or facts, such as the signs of a pressure ulcer) and things they need to be able to DO (explain how to use a catheter or use a Hoyer lift, for example). Let’s talk first about what people with tetraplegia need to know. What knowledge have you gained that has helped you direct your care well?
 - a) Can you recall a situation where you had difficulty directing care because there was something you didn’t know? What didn’t you know? What happened?
 - b) Can you recall an instance where a caregiving situation went really well because of some knowledge you had gained? What was that knowledge? How was it helpful to you and/or your caregiver?

- c) What do you know now that you didn't know when you were first starting to direct your care?
 - d) How did you gain the knowledge you were missing? Practice? Trial and error? Advice from others? Resources on the web or elsewhere?
 - e) *[Skip if previously addressed in Q1]* How much of your knowledge about directing care came from formal training? What other sources of knowledge were helpful to you?
- 3) **Let's talk now about the kinds of things that people with tetraplegia need to DO—the SKILLS they need to learn. Examples might include being able to clearly communicate what you want or need to have done, monitoring the helpers when they do it, giving feedback, etc. What kinds of things have you learned to do or say to direct care well, or to work well with your caregivers?**
- a) Can you recall an instance where your care went badly because you didn't give the right kind of instructions or feedback? What happened?
 - b) Can you recall an instance where a caregiving situation went really well because of something you said or did? What happened?
 - c) What are some examples of things you were not good at when you first started to direct your care, but got better at over time?
 - d) How did you gain the skills you were missing? Practice? Trial and error? Training from others? Resources on the web or elsewhere?
 - e) *[Skip if previously addressed in Q1]* How much of your caregiving skills came from formal training versus other methods of learning? What methods did you use to gain the skills you needed?
- 4) **What interpersonal skills (communication skills, managing personality dynamics, etc.) have you found to be important to work well with caregivers? Why are they important?**
- a) How did you learn those skills?
 - b) To what extent were those skills addressed in formal training? How much did you learn outside of formal training?
 - c) What changes would you like to see in how those topics are addressed in training?
- 5) **To what extent have you been involved in teaching a caregiver to perform tasks for you?**
- a) *[If at least some participants involved in teaching]* What process do you use to teach caregivers how to assist you?
 - b) What process do you use to determine whether your caregiver is doing a good job? Do you let them try it and then give them feedback? Do you first quiz them on information about the task, and then let them try it? Are there other strategies you use?

- c) What feedback do you provide your caregivers to help them assist you properly?
 - i) *[Skip if time concerns] If you have a long-term caregiver: do you still give this person feedback? How does it differ from the feedback you gave him/her when you first taught them?*

6) How would you describe your best caregivers?

- a) What characteristics do they have?
- b) What do they do that makes them the best?

7) How would you describe the caregivers who weren't so good?

- a) What characteristics did they have?
- b) What problems did you encounter when trying to work with them?
- c) Was there anything you did or said that helped you work better together?

8) From a variety of sources, I have compiled a list of activities with which caregivers may assist. [Show list] Which do you consider to be the most important? Why?

- a) Are there other tasks that you or other SCI caregivers assist with that are not listed here?
- b) Which caregiving tasks do you think are the most difficult, for you and/or for your caregiver? What makes them difficult? Is it the complexity of the task? The knowledge required? The physical demands? The awkwardness (as with many aspects of bowel and bladder management? Dynamics of the relationship between you and the person you are assisting?
- c) Which tasks are the easiest? What makes them easy?

9) If you were in a position to help design a training program for people with tetraplegia and their caregivers, what would it look like?

- a) What skills or information do you think should be taught to people with tetraplegia? To caregivers?
- b) How should learning over time be tested?
- c) What kinds of feedback should be provided? In what form? By whom?
- d) What criteria should be used to determine whether the person with tetraplegia is doing what he/she should? (How should his/her care direction performance be evaluated?)

- e) What criteria should be used to determine whether caregivers are doing what they should?
(How should care provision be evaluated?)

Additional Questions to Ask if Time Permits

- 10) *[Skip if challenges emerged well in previous questions]* What challenges did you encounter as you started to work with caregivers?
 - a) Were there things that were hard to explain or other problems directing your care? What were these?
 - b) Were there things that were hard for your caregiver to do or other problems with your care? What were these?
 - c) What helped you overcome the challenges you encountered?
- 11) To what extent does the way you direct care differ when you are directing a family member or friend versus a hired caregiver? How is it different?
 - a) Should the ability of a person with tetraplegia to direct care be judged differently when he/she is directing a family member/friend versus a hired caregiver? If so: how is the judging different? Remember, we are talking here about judging the ability of the person with tetraplegia to direct care, not the caregiver's ability to perform the care task.
 - b) Should the ability of a hired caregiver be judged differently than that of a friend/family member? If so: how is the judging different?
- 12) *[Skip if skills and knowledge addressed well in previous questions]* How would you describe an expert caregiver? What do they know? What are they able to do?
- 13) What advice would you give to a person who is newly-injured to help him or her work well with caregivers?
- 14) If I wanted to know whether a caregiver is doing a good job providing care to a person with tetraplegia, what is the best way to find out? Should I interview the caregiver? Interview the person he/she is assisting?
 - a. Would I get different answers? Why? In some areas of care more than other areas?
 - b. Would I need to observe how the caregiver works with the person he/she is assisting? Would I come up with different opinions than I would get from an interview? Why or why not?

- c. To get a good idea of how well a caregiver provides care, would I need to ask about *[or observe, depending on answer to previous question]* all the different tasks that he/she might help with? Or would it be enough to see only some tasks?
 - i. If some would be enough, which ones might tell me the most about how well a person can direct his/her own care?
 - ii. *[Skip if difficulty of tasks were addressed previously]* Are there particular tasks that are hard to perform? Which are they?
 - iii. *[Skip if difficulty of tasks were addressed previously]* Are there tasks that are easy to perform? Which are they?
- 15) If I wanted to know whether someone with tetraplegia is doing a good job directing his care, what is the best way to find out? Should I interview him? Interview the caregiver?
- a) Would I get different answers? Why?
 - b) Would I need to visit him and observe how he directs his/her helper? Would I come up with different ideas about his/her ability than I would get from an interview? Why or why not?
 - c) To get a good idea of how well a person with tetraplegia can direct care, would I need to ask about *[or observe, depending on answer to previous question]* all the different tasks that he/she might direct? Or would it be enough to see only some tasks?
 - i) If some would be enough, which ones might tell me the most about how well a person can direct his/her own care?
 - ii) *[Skip if difficulty of tasks were addressed previously]* Are there particular tasks that are hard to direct? Which are they?
 - iii) *[Skip if difficulty of tasks were addressed previously]* Are there tasks that are easy to direct? Which are they?
 - d) Do you think a person with SCIs' health condition is good indicator that he/she is doing a good job directing his/her care? Why or why not?
 - e) Do you think a person with SCI's health condition is a good indicator that the person's caregivers are doing a good job? Why or why not?

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Focus Group Questions for Caregivers of People with Tetraplegia MASTER QUESTION LIST for Study Team
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VERIFY RECORDERS ARE TURNED ON BEFORE STARTING DISCUSSION

16) What is your relationship to the person to whom you provide care (parent, spouse, employee, etc.)?

17) How did you learn to be a caregiver for a person with tetraplegia?

- i) Who taught you?
- j) How did they teach you?
- k) When did that teaching happen?
- l) Was the teaching you received clear? How much did you have to improvise or try-and-fail once actual caregiving started?
- m) Did you receive training in inpatient rehabilitation? If so, what could the rehab team have done differently during inpatient rehab to better prepare you?
- n) How much did you learn about caregiving through formal training (by rehab professionals) versus trial-and-error or other means? What other things (besides formal training) helped you learn to be a good caregiver?
- o) *[Skip if time concerns]* How was feedback given while you were learning?
- p) *[Skip if time concerns]* What kinds of feedback were most helpful?

18) To provide good care, there are things that caregivers need to KNOW (information or facts, such as the signs of a pressure ulcer) and things they need to be able to DO (skills such as such as how to use a catheter or perform a transfer). Let's talk first about what caregivers need to know. What knowledge have you gained that has helped you be a good caregiver for the person you assist?

- f) Can you recall a situation where you had difficulty providing care because there was something you didn't know? What didn't you know? What happened?
- g) Can you recall an instance where a caregiving situation went really well because of some knowledge you had gained? What was that knowledge? How was it helpful to you and/or your loved one/client?
- h) What do you know now that you didn't know when you were first starting to be a caregiver?
- i) How did you gain the knowledge you were missing? Practice? Trial and error? Advice from others? Resources on the web or elsewhere?
- j) *[Skip if previously addressed in Q1]* How much of your knowledge about caregiving came from formal training? What other sources of knowledge were helpful to you?

19) Let's talk now about the kinds of things that caregivers need to DO—the SKILLS they need to learn. What kinds of tasks have you learned to do on behalf of the person you assist? (Examples include performing transfers, using a urinary catheter, assisting with a bowel program, using special equipment, etc.)

- f) Can you recall a situation where you had difficulty providing care because there was a task or step you forgot to do or did incorrectly? What happened?
- g) Can you recall an instance where a caregiving situation went really well because of something you did really well? What happened?

- h) What are some examples of tasks you were not good at when you first started to give care, but got better at over time?
- i) How did you gain the skills you were missing? Practice? Trial and error? Training from others? Resources on the web or elsewhere?
- j) *[Skip if previously addressed in Q1]* How much of your caregiving skills came from formal training versus other methods of learning? What methods did you use to gain the skills you needed?

20) From a variety of sources, I have compiled a list of areas in which care may be provided. *[Show list]* Which do you consider to be the most important for caregivers of a person with SCI to learn?

- d) Are there other tasks that you or other SCI caregivers assist with that are not listed here?
- e) Which caregiving tasks are most difficult for you? What makes them difficult? Is it the complexity of the task? The knowledge required? The physical demands? The awkwardness (as with many aspects of bowel and bladder management? Dynamics of the relationship between you and the person you are assisting?
- f) Which tasks are the easiest for you? What makes them easy?

21) One of the things that we would like to help people with tetraplegia to do is to be able to take an active role in “directing their care.” By that I mean the process of telling their caregivers what needs to be done and giving them instructions about how to do it.

- a) To what extent do you receive direction of care from the person you assist?
- b) Can you think of a time when the person you help did not properly direct you? What happened?
- c) Can you think of a time when the person you help directed you really well, and perhaps a problem was avoided? What happened?
- d) What feedback do you find most helpful from the person you help?

22) If you were in a position to help design a training program to help prepare caregivers for people with tetraplegia, what would it look like?

- a) What skills or information do you think should be taught?
- b) How should learning over time be tested?
- c) What kinds of feedback should be provided? In what form? By whom?
- d) What criteria should be used to determine whether a caregiver is doing what they should? (How should their caregiving performance be judged?)

Additional Questions to Ask if Time Permits

23) What challenges did you encounter as you learned to be a caregiver? What helped you overcome those challenges?

24) What interpersonal skills (communication skills, treating each other with respect, managing personality dynamics) have you found to be important to provide good care to the person you assist?

- a) To what extent were those skills addressed in formal training? How much did you learn outside of formal training?
- b) What changes would you like to see in how those topics are addressed in training?

25) *[Skip if skills and knowledge addressed well in previous questions]* How would you describe an expert caregiver? What do they know? What are they able to do?

- 26) What advice would you give to new caregivers about how to provide good care?
- 27) If I wanted to know whether a caregiver is doing a good job providing care to a person with tetraplegia, what is the best way to find out? Should I interview the caregiver? Interview the person he/she is assisting?
- d. Would I get different answers? Why? In some areas of care more than other areas?
 - e. Would I need to observe how the caregiver works with the person he/she is assisting? Would I come up with different opinions than I would get from an interview? Why or why not?
 - f. To get a good idea of how well a caregiver provides care, would I need to ask about [*or observe, depending on answer to previous question*] all the different tasks that he/she might help with? Or would it be enough to see only some tasks?
 - i. If some would be enough, which ones might tell me the most about how well a person can direct his/her own care?
 - ii. Are there particular tasks that are hard to perform? Which are they?
 - iii. Are there tasks that are easy to perform? Which are they?
- 28) If I wanted to know whether someone with tetraplegia is doing a good job directing his care, what is the best way to find out? Should I interview him? Interview the caregiver?
- a) Would I get different answers? Why?
 - b) Would I need to visit him and observe how he directs his/her helper? Would I come up with different ideas about his/her ability than I would get from an interview? Why or why not?
 - c) To get a good idea of how well a person with tetraplegia can direct care, would I need to ask about [*or observe, depending on answer to previous question*] all the different tasks that he/she might direct? Or would it be enough to see only some tasks?
 - i) If some would be enough, which ones might tell me the most about how well a person can direct his/her own care?
 - ii) Are there particular tasks that are hard to direct? Which are they?
 - iii) Are there tasks that are easy to direct? Which are they?
 - d) Do you think a person with SCIs' health condition is good indicator that he/she is doing a good job directing his/her care? Why or why not?
 - e) Do you think a person with SCI's health condition is a good indicator that the person's caregivers are doing a good job? Why or why not?

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Focus Group Questions for SCI Clinicians MASTER QUESTION LIST for Study Team

VERIFY RECORDERS ARE TURNED ON BEFORE STARTING DISCUSSION

- 1) What do you teach people with tetraplegia about direction of care?**
 - a) What knowledge do they need to be successful?
 - b) What skills do they need to be successful?

- 2) What do you teach the caregivers of people with tetraplegia about caregiving?**
 - a) What knowledge do they need to be successful?
 - b) What skills do they need to be successful?
 - c) Are there things you teach people with tetraplegia but not their caregivers? Vice versa?

- 3) In your current practice, how do you assess direction of care skills?**
 - a) When are assessments done?
 - b) How are they done? Do you use a checklist or rating scale?
 - c) What indicators are you looking for to assess how well a person with tetraplegia can direct his/her own care?
 - d) *[Skip if time concerns] How are direction of care skills documented?*

- 4) In your current practice, how do you assess caregivers' ability to provide care?**
 - a) When are assessments done?
 - b) How are they done? Do you use a checklist or rating scale?
 - c) What indicators are you looking for to assess how well a caregiver can provide care?
 - d) *[Skip if time concerns] How are caregivers' abilities documented?*

- 5) What challenges do you currently encounter when assessing direction of care or caregiving skills?**
 - a) To what extent could an assessment tool help address these challenges?

- 6) What characteristics would you like an assessment tool for direction of care and caregiving skills to have to make it useful in clinical practice?**
 - a) What content should it have?
 - b) What would help make it easy to use?
 - c) What method would you use to complete it? (Observation? Interview? Simulated tasks or role-playing?)
 - d) Should direction of care and caregiver's abilities be addressed in one tool or should there be separate tools for direction of care and for caregiving?

- 7) How do you envision using an assessment tool(s) for direction of care/caregiving skills?**
 - a) How often would you likely complete it?
 - b) Who would complete it?
 - c) When would you complete it?
 - d) With whom would you share the scores?
 - e) In what context would the assessment findings be shared? (Team conference, family meetings, other?)

- f) How would you use the results?
- 8) What barriers do you anticipate to using the tool?**
- a) How might these be overcome?
- 9) How detailed should the assessment tool be with respect to the activities that are being directed or performed? Should there be questions about each activity that might be relevant to the person with tetraplegia (such as transfers, bladder management, etc.)? Or should the tool look more globally at abilities or skills that cross different types of activities?** (Examples of abilities that cross different activities include: Determining need for a particular care task, determining what supplies are needed, providing clear instructions, recognizing errors, correcting errors, etc.)
- i) *[If a preference for specific activities is given]* I have compiled a list of areas in which care may directed or provided *[see handout]*. Which would be most important to include in a tool? Are there others that are not listed that should be included?
- ii) *[If a preference for cross-activity abilities is given]* What kinds of knowledge, abilities or skills cross multiple tasks?
- 10) What criteria should be used to assess how well a person with tetraplegia is able to direct his/her own care?**
- a) Are these criteria consistent from task to task (transfers vs. catheterization, for example), or do different criteria need to be applied to different tasks?
- b) Do the criteria differ based on the nature of the caregiver (age, sex) or the patient-caregiver relationship?
- 11) What criteria should be used to assess how well caregivers can provide care?**
- a) Are these criteria consistent from task to task (transfers vs. catheterization, for example), or do different criteria need to be applied to different tasks?
- b) Do the criteria differ based on the nature of the caregiver (age, sex) or the patient-caregiver relationship?

Additional Questions to Ask if Time Permits

- 12) To what extent do you address interpersonal issues (communication skills, mutual respect between caregivers and people with tetraplegia, avoidance of infantilizing the person with tetraplegia, etc.) in your patient/caregiver training?**
- a) What interpersonal skills (if any) should the assessment tool include?
- 13) We would like the assessment tool to help us tell the difference between those people who have a very basic level of skill at direction of care or caregiving, those who are experts, and others who are in-between.**
- a) Which direction of care skills are the most basic? Which are the most advanced? Which are somewhere in the middle?
- i) *[if a 'that depends' answer]* What makes a directing care skill basic or advanced? Is it the physical demands of the task? The number of steps? Extent to which specialized knowledge is needed? Characteristics of the person with SCI? Of the caregiver? Of their relationship (e.g. spouse vs. hired help)?
- b) How about caregiving—which skills are most advanced versus most basic? In the middle?
- i) *[if a 'that depends' answer]* What makes a caregiving skill basic or advanced? Is it the physical demands of the task? The number of steps? Extent to which specialized knowledge

is needed? Characteristics of the person with SCI? Of the caregiver? Of their relationship (e.g. spouse vs. hired help)?

- 14) What kind of rating scale should be used to describe direction of care or caregiving ability?
 - a) We reviewed a selection of inpatient rehabilitation charts to get a sense of how the ability to direct or provide care is described in clinical documentation. *[Refer to handout]* Which of these (if any) do you think might be useful in an assessment tool?
 - b) Should different ways of describing ability be used for direction of care versus caregiving?
- 15) What methods do you currently use to communicate information about direction of care ability? In progress notes? Orally in team conference?
 - a) With whom do you communicate about the caregivers' ability to provide care?
 - b) What methods are used to communicate information about caregivers' ability to provide care? In progress notes? Orally in team conference?
 - c) How is information about direction of care and caregiving skill used to make decisions about the patient's care or to formulate future patient/caregiver training plans?

APPENDIX 4

Themes and Their Implications for Assessment Tool Development

Themes/Ideas Shared	Constituencies Who Expressed These Ideas	Implications for Assessment Tool Development and/or Use
<p><i>An assessment tool would be valuable in inpatient rehabilitation (and rehabilitation in general) in several ways:</i></p> <ul style="list-style-type: none"> • Provides an indicator of readiness for discharge, which helps both the rehabilitation team and third-party payers who may be asked to authorize more days in rehabilitation to allow for continued training • Helps identify areas where patient/family need additional caregiving resources after discharge. • Helps people with tetraplegia (PWTs) and caregivers understand the scope of the skills they need to learn to return to the community; would serve as a basis of discussion with family members during the process of scheduling family training • Promotes a sense of accomplishment among PWTs and caregivers as they work on skills and see change over time • Helps outpatient therapists and others in the continuum of care be able to “pick up where they [inpatient rehabilitation] left off” and continue direction of care and caregiving education beyond inpatient rehabilitation discharge • Opens opportunities for discussion of sensitive topics between family and patient 	Clinicians	Confirms that an assessment tool for direction of care/caregiving skills is considered valuable by clinicians and is expected to improve the direction of care/caregiving training process.

<ul style="list-style-type: none"> • Facilitates identification of resource gaps and planning for additional help at home; or planning for alternative discharge settings • Would improve communication about direction of care/caregiving skills by putting summary in one place in the chart. 		
<p><i>The types of tasks with which PWTs may need assistance are wide and varied, encompassing nearly all aspects of life.</i></p> <p>Activities and tasks that relate to safety and the prevention of complications were considered the most important. Examples of such tasks included:</p> <ul style="list-style-type: none"> • Proper hygiene • Bowel management • Bladder management • Recognition of and response to autonomic dysreflexia • Positioning (to protect skin, prevent or lessen pain) • Prevention of burns (water temperature, keeping body parts away from hot objects) • Transferring/Lifting or moving PWT by caregiver • Stretching • Mat mobility skills • Skin care <p>PWTs also described working with caregivers on tasks not directly related to health and functioning including:</p> <ul style="list-style-type: none"> • Clothing care • Home cleaning and maintenance • Financial transactions and record-keeping 	All	<p>The list of activities and tasks considered particularly important will help prioritize the types of tasks that should be assessed using the tool.</p> <p>To balance comprehensiveness and utility, one approach might be for the tool to allow ratings of direction of care/caregiving skill to be given for general task areas in which care direction or caregiving might be provided (bladder management, positioning, etc.), rather than for very specific tasks within those areas.</p> <p>We will consider the extent to which it may be appropriate to include non-medical/functional task areas in the tool.</p>

<p><i>Communication skills are critical for successful direction of care/caregiving.</i></p> <p>Examples of skills that were considered important for successful PWT-caregiver collaboration included ability to:</p> <ul style="list-style-type: none"> • Provide instructions that are specific, detailed, and clear • Recognize when the person with whom you are working is confused or frustrated (through body language, facial expression, comments provided, etc.) • Provide criticism constructively when needed • Speak in a respectful manner to the person with whom you are working (includes use of appropriate language and tone of voice, saying please and thank you, etc.) • Be an active listener 	All	<p>It may be beneficial for the tool to include items that address communication as an activity in itself (in addition to bowel management, bladder management, etc.) so that level of communication skill can be described--and improved upon--over time.</p>
<p><i>Knowing why a particular care task is important and being able to convey that is critically important to:</i></p> <ul style="list-style-type: none"> • Engage the PWT and caregiver during the training process • Facilitate positive interpersonal dynamics between the PWT and caregiver (so that caregivers understand that when a certain request is being made it is for a legitimate and important reason) • Help caregivers feel respected (that they are contributing to something important) • Generalize the knowledge to specific situations that may come up, but that can't be anticipated (to facilitate problem-solving) 	All	<p>Should consider including content in the tool that allows assessors to rate:</p> <ul style="list-style-type: none"> • Knowledge of importance of care tasks • Ability to convey information about the importance or relevance of a care task to others

<p><i>PWTs must develop confidence and learn to speak up for themselves if a problem is occurring.</i></p> <p>PWTs expressed hesitance to speak up when they were newly-injured due to feelings of vulnerability. They expressed fear of angering the person on whom they depend and the retaliation that could result, or were concerned they might lose that caregiver and have difficulty finding another. However, over time they learned that not speaking up created worse problems in the long run, and eventually developed the confidence to advocate for their needs and preferences.</p> <p>Knowledge of care also contributes to confidence to speak up.</p>	<p>PWTs and Clinicians</p>	<p>Self-advocacy may be important to include as a skill to be rated.</p>
<p><i>The ability to problem-solve is important to facilitate a successful return home.</i></p> <p>The ability to change the way a task is being done to address a problem or accomplish it under less than ideal conditions is considered a sign of expertise on the part of the care director or caregiver. All scenarios cannot be anticipated or trained for—some creativity will be required in real life.</p>	<p>Primarily clinicians, but addressed indirectly by PWTs and Caregivers</p>	<p>Ability to problem-solve or perform a skill under challenging conditions may be criteria for the “high end” of the ability rating scale.</p> <p>Consider several aspects of ability when scoring:</p> <ul style="list-style-type: none"> • Knowledge of how • Knowledge of why • Ability to verbalize • Execution (efficiency/safety/failure rate) • Ability to generalize (problem solve)
<p><i>You have to know yourself and your body before you can really direct your care well.</i></p> <p>Over time, important things learned included:</p> <ul style="list-style-type: none"> • Triggers for episodes of autonomic dysreflexia and what it feels like 	<p>PWTs/ Caregivers</p>	<p>Suggests that the tool should include knowledge-oriented items or rating scales that address key signs and symptoms of problems that may require intervention by the PWT and/or caregiver.</p>

<ul style="list-style-type: none"> • Triggers for pain (and how pain effects one's mood and tolerance for social or physical activity) • Triggers for spasms • Signs of urinary tract infection 		
<p><i>Barriers to learning direction of care/caregiving skills in inpatient rehabilitation include:</i></p> <ul style="list-style-type: none"> • Denial – both PWTs and caregivers may regard their situation as temporary, and may feel they do not need to learn various care tasks • Ever shorter lengths of stay – reduces time available for training • Being overwhelmed – there are so many new and unfamiliar things to deal with and learn in a very short period of time; PWTs are often still medically fragile; there is a limit to what one can absorb • Availability of caregivers – may not be present until near the end of rehabilitation, forcing all instruction to be squeezed into a short period of time • Capability of caregiver(s) - Family caregiver may not be psychologically or physically able to execute certain tasks 	All	<p>These concepts provide information on the psychosocial, medical, and logistical context in which the tool will be applied.</p> <p>Underscores the need to create an instrument that will be useful both in inpatient rehabilitation and in later stages of care, since learning must continue over time</p> <p>Will be helpful for the tool to allow direction of care to be assessed even if the designated caregiver has not yet been trained in caregiving skills.</p>
<p><i>Time and experience (“on the job training”), trial and error were the primary ways that PWTs learned direction of care skills.</i></p> <p>Note: Caregivers were more likely than PWTs to say that they received the training they needed from clinicians during inpatient rehabilitation, though both PWTs and caregivers acknowledged that they learned more over time as greater experience was gained.</p>	PWTs	<p>Reinforces the idea that learning direction of care/caregiving skills extends well beyond the start of training in inpatient rehabilitation, and that the tool should be designed in a manner that allows use across the continuum of care. – including for outpatient care environments so that clinician can know which areas need further instruction.</p> <p>Suggests that the training received in inpatient rehabilitation may have been inadequate.</p>

		Underscores the need to improve the direction of care training process to better prepare PWTs for a transition to home. The assessment tool will help fill this need by improving assessment of ability over time so that training can be targeted to areas of greatest need.
<p><i>Everything is different once you get into “the real world.”</i></p> <p>Examples included using different equipment at home versus in the hospital, using different techniques (clean vs. sterile for bladder management, for example), and access to supplies (unlimited in hospital, limited at home).</p>	All	<p>Suggests that assessing care direction and caregiving in circumstances that mimic the home environment as much as possible will be helpful in getting assessment scores that will most closely align with what is likely to occur after discharge; also reinforces the idea that direction of care/caregiving skills continue to develop over time.</p> <p>Also reinforces importance of problem-solving-- all scenarios cannot be anticipated and trained for and PWT/CG will need to generalize/problem solve.</p>
<p><i>Most caregivers have little familiarity with the special issues of SCI, even if they are certified or licensed assistants.</i></p> <p>The training provided by agencies is generally inadequate to prepare caregivers, so the person with SCI (and/or his/her family) should expect to do basic teaching about SCI and how it affects the body as well as a lot of on-the-job training in how to provide care.</p>	PWTs, Caregivers	Reinforces the importance of training PWTs to direct their care.
<p><i>Need to balance the level of detail in the tool with utility. A tool that is too long or detailed will be cumbersome to use.</i></p> <ul style="list-style-type: none"> • Clinicians wanted a tool that was comprehensive but allowed some degree of customization or ability to 	Clinicians	A tool that addresses general task areas (wheelchair management, bladder management, etc.) will likely be more manageable to use than one that breaks tasks

<p>rate only those items that applied to a particular person.</p> <ul style="list-style-type: none"> Expressed a desire for a “write in” area that could give more specific information about the tasks being assessed (such as specifying “intermittent catheterization” or “Foley” under bladder management). 		<p>down into detailed subtasks, which may be unique to the individual.</p> <p>We will consider the suggestion given by clinicians to include a “write in” area that provides additional detail about the specifics of the tasks they were rating for a given individual (sliding board transfer from bed to manual wheelchair, for example).</p>
<p><i>Tool would be easiest to complete if it assessed behavior over a period of time rather than a single point in time (since there may not be an opportunity to assess all tasks on that day).</i></p>	Clinicians	<p>Will consider a 1-2 week look-back period for scoring as suggested by clinicians.</p>
<p><i>Multiple disciplines should be involved in scoring.</i></p> <p>Not yet certain if best to assign certain task areas to certain disciplines or allow whoever sees a task first during the scoring period to give the score</p> <p>Respiratory therapy and recreation therapy also recommended as playing a role, especially respiratory therapy because of the special skills, knowledge and risks: sterile procedure for suctioning and problem-solving ventilator issues.</p>	Clinicians	<p>Further discussions will need to be had about the preferred “division of labor” for instrument scoring. All disciplines expressed interest in contributing to the scoring process.</p> <p>Respiratory, recreation and psychology (not present in focus groups) were mentioned by the focus group participants and could be possible completers of the assessment tool.</p>
<p><i>Clinicians use a variety of methods to teach PWTs and caregivers, including:</i></p> <ul style="list-style-type: none"> Didactic instruction Demonstration (sometimes using models) Providing feedback or physical assistance while PWTs and caregivers practice a skill 	Clinicians	<p>Provides context for use of tool.</p>

<ul style="list-style-type: none"> • Role-playing (therapist may ask person with tetraplegia to instruct them in doing a task, as though they were a novice caregiver; may purposely do something wrong to give PWT opportunity to provide corrective feedback) • Allowing a caregiver to practice a skill with the therapist acting as the patient (may help caregiver be less afraid of causing harm and may help the PWT better see the steps of the task to facilitate self-direction later) 		
<p><i>Assessment of care direction/caregiving skills is an ongoing process, mostly accomplished by observation</i></p> <p>Clinicians suggested that it might be useful for PWTs and/or caregivers to be able to score themselves on tasks so that differences in perception between the providers and recipients of training could be assessed</p>	Clinicians	<p>Completion of the assessment tool would likely occur through observation</p> <p>Will try to create scoring criteria that are easily understood by PWTs, caregivers, and clinicians to facilitate self-assessment as well as assessment by clinicians</p>
<p><i>Safety of skill performance is a key criterion for determining readiness for discharge</i></p> <p>Clinicians suggested that the assessment tool scoring system should “weight” certain items that MUST be able to be done safely prior to return home.</p>	Clinicians	<p>Safety of task performance will be included among the scoring criteria and consideration will be given to weighting scores or taking other steps to emphasize the importance of safe performance of tasks.</p>
<p><i>A successful PWT-caregiver interaction requires the engagement of both parties; deficits in one can be made up for by strengths of another (a good care director can compensate for a poor caregiver and vice versa)</i></p> <ul style="list-style-type: none"> • Clinicians reported that they often begin assessing the care direction skills of the PWT earlier than the skills of the caregiver due to caregiver availability 	Clinicians	<p>We will consider a three part scoring system that provides scores for the PWT, caregiver, and dyad.</p>

<p>(or lack thereof); wanted to have a tool that would enable scoring of care direction, even in the absence of a caregiver-in-training</p> <ul style="list-style-type: none"> o Clinicians expressed a desire to be able to score the performance of the caregiver separately from the PWT, but to also be able to give an overall score for the pair working together 		
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APPENDIX 5

Master List of Tasks/Knowledge Areas for People with Tetraplegia and/or their Caregivers

(Provided to participants during review of initial drafts of TEAM Tool prior to piloting)

Focus group participants named many types of daily activities with which help might be needed, as well as certain skills or areas of knowledge that are important for directing or providing care. To help us decide what should be included in the assessment tool we are trying to create, we have listed these tasks/skills/knowledge areas here for your reference during our discussions. We have tried to group them into separate categories when possible, but acknowledge that many could go into more than one category.

<p><u>Communication Skills/Interpersonal Dynamics</u></p> <ul style="list-style-type: none"> • Coming up with the language/words to express how to carry out specific activities or tasks (including using terminology that is appropriate for the audience) • Being specific about how to do tasks • Knowing entire process of a task [so can explain it] • Not being rude or impatient (knowing how you are perceived) • Having skills/confidence to self-advocate (to correct caregiver when needed) • Being calm • Ability to read “social cues”, awareness of feelings/emotions, including level of frustration • Exercising patience • Exercising assertiveness • Communicating personal goals • Setting expectations early • Establishing your “priority list” (what is critical versus what you can “let go”) • Learning how to ask for help • Creating a healthy relationship, building rapport • Knowing how to set boundaries • Ability to negotiate • Knowing how to acknowledge and address emotional needs 	<p><u>Problem-Solving</u></p> <ul style="list-style-type: none"> • Confidence to adapt • Knowledge to adapt • Knowing who to contact for various repairs (wheelchair, van, etc.) • Knowing where/who resources are for care • Anticipating what could go wrong • Learning strategies for when something goes wrong • How to do a task in less than ideal conditions • Always having ways of communicating (sleeping with phone, Life Alert Systems, etc.) • What to do if attendant does not show up • Recognizing the right kind of person to help you if you are in public (age, strength, trustworthiness ...) • Learning and mastering self-responsibility • Creativity - innovative ways to help with/manage persistent problems • Flexibility - willingness to change routines between caregiver and care recipient <p><u>Training or Managing Care Providers (Particularly Hired Staff)</u></p>
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<ul style="list-style-type: none"> • As caregiver, communicating what you are about to do to before you do it (no surprises) • Listening to the person with tetraplegia • Managing caregiver emotions • Managing loss of privacy/discretion/dignity • Respecting the person with tetraplegia • Expressing thanks • Need to recognize and understand how to engage person who is not cooperating • Engaging complicated family dynamic (particularly as hired caregiver in the home) • Stepping back and evaluating the situation • Asking for feedback • Sensitivity to generational, cultural, language differences 	<ul style="list-style-type: none"> • Coordinating communication among caregivers • Managing caregiver schedules • Establishing rules and policies • Conducting "check-in" meetings to discuss each other's schedules, needs in general, etc. • Assessing the caregiver's ability to provide care • Knowing how to train caregivers, including what format to use for teaching (talking, demonstration, videos, etc.) • Making mental checklists and explicit checklists • Writing task or instructions down • Interviewing candidates • Firing caregivers when needed • Managing time • Being organized
<p><u>Self-Awareness</u></p> <ul style="list-style-type: none"> • Being very observant • Monitoring their body system • Knowing your skin (how it looks normally so can identify changes) • Understanding changes in how your body works (physiology) with tetraplegia • Observing signs of presence of problem (such as increase spasticity as a sign of urinary tract infection) • Understanding meaning behind different kinds of spasms (not taking medications, pain, urinary tract infection, etc.) <p><u>Breathing (Respiratory Care)</u></p> <ul style="list-style-type: none"> • How to let someone know if ventilator not working right • How to manually bag in case of emergency (vent failure, power outage, etc.) • Expertise in utilizing every feature of coughlator or ventilator 	<p><u>Bowel</u></p> <ul style="list-style-type: none"> • Bowel program (what it involves) • What to do if an involuntary (bowel accident) occurs • Taking Senna (at right time before bowel program) • Medications for bowel program • Positioning for bowel program • Suppository insertion • Timing and frequency of bowel program • Digital stimulation • Avoiding/managing hemorrhoids <p><u>Bladder</u></p> <ul style="list-style-type: none"> • Intermittent catheterization • Hygiene of self and equipment • Sterile technique • Clean technique • Recognizing signs of urinary tract infection • What to do if urine smells or is concentrated

<ul style="list-style-type: none"> • How to perform assisted cough (hand placement, body position, etc.) • How to clear mucus (secretions) using suctioning or other means • How to travel with ventilator or other equipment <p><u>Bathing/Grooming</u></p> <ul style="list-style-type: none"> • Washing body (via shower, bed bath, etc.) • Brushing teeth • Combing/styling hair • Washing face • Use of shower chair or other equipment • Kind of equipment you use for shaving and brushing teeth • Risk of hot water • Thorough bathing <p><u>Dressing</u></p> <ul style="list-style-type: none"> • Choosing clothes that meet the preferences of the wearer • Putting shoes on properly • Type of shoes (cannot be too hard) • Manipulating pants 	<ul style="list-style-type: none"> • Recognizing signs of catheter problems • How to avoid catheter-acquired urinary tract infections • Foley (Indwelling) catheterization • Changing Foley catheter (know that it needs to be changed and doing it correctly) • Flushing catheter • Emptying leg bag • Changing leg bag correctly and detecting problems • Switch from leg bag to night bag • How to put the urinal on <p><u>Eating/Drinking</u></p> <ul style="list-style-type: none"> • Positioning for feeding, especially when there is a G-tube (stomach tube) • Positioning cup just right to keep on lap • Feeding (e.g., cutting food into right size, providing it at right rate) • Hydration
<p><u>Positioning</u></p> <ul style="list-style-type: none"> • Tilt-in-space (how to use feature, how far tilted the person with tetraplegia wants/needs to be) • Splints (types, how to use) • How to position properly in bed, wheelchair, and on other support surfaces • Managing the draw sheet for turning • Proper pillow placement • Performing position changes/transfers in different ways at different times depending on the situation • Positioning for feeding, especially when there is a G-tube (stomach tube) 	<p><u>Equipment</u></p> <ul style="list-style-type: none"> • Durable medical equipment in general (use, maintenance, safety, hygiene) • How to travel with assistive equipment • How to use transfer equipment (hoyer lift, sliding board) • Knowing color/type of loops for mechanical transfer • Transfer board – how to lift your leg, lean at an angle • Using manual lifts versus power lifts • Hoyer lift with brace • Use of seatbelt, proper tightness • Shower equipment management • Kind of equipment you use for shaving and brushing teeth

<ul style="list-style-type: none"> • Managing orthostasis (low blood pressure related to position) from positioning standpoint • Positioning to prevent contractures • Proper position of shoulders • Supporting arms (to avoid subluxation) • Safety--Not pulling on arms during positioning, transfers <p><u>Skin</u></p> <ul style="list-style-type: none"> • Knowing what your skin normally looks like • Awareness of lack of sensation and risks posed related to temperature • Be aware of things in your surroundings that can cause burns (wheelchair cushions, armrests are dark colored and can get hot in summer sun; hot pizza box; sitting too close to fire or heater; hot water; etc.) • Knowing signs of skin problems (redness leads to blister leads to...) • Skin inspection and proper response (to redness or other signs) • Wheelchair cushion use/maintenance • Weight shifting (multiple ways to do it) • Cleaning and drying skin properly • Moisturizing, lotioning • Using tilt in space • Risk for skin or breakdown • Wound prevention and care • Avoid pinching skin (to avoid blisters) • Pressure points • Turning • Padding • Risk to feet and toes (not realizing injury because couldn't feel it) 	<ul style="list-style-type: none"> • Assistive technology for cell phone, computer, TV, iPad • Using and maintaining power wheelchairs, manual wheelchairs • How to turn power chair on • How to access manual features of power chair • How far a chair tilts • Assist in positioning or transferring if chair gets stuck in certain position • Knowing that the mattress at home is not like the mattress in inpatient rehab • Mattress/cushion maintenance (checking air levels, cleaning, etc.) • Troubleshooting equipment – what to do if something breaks • How to order replacement parts or other adaptive gear • Using ramps (temporary ramp or permanent) • Use of writing devices, mouth sticks • Bracing <p><u>Domestic/Housekeeping</u></p> <ul style="list-style-type: none"> • Cooking/food preparation • Food shopping • Cleaning house and other household chores • Laundry, ironing • Child care • Cooking • How to prepare food as preferred by client • Ordering supplies • Supply placement on shelf so supplies are accessible
<p><u>Transfers</u></p> <ul style="list-style-type: none"> • Position changes/transfers in different ways at different times • Hoyer transfers • Using manual lifts versus power lifts 	<p><u>Exercise</u></p> <ul style="list-style-type: none"> • Range of motion/Stretching routine • Strengthening routine • Knowing not to stretch hands to preserve tenodesis

- Sliding board transfer (how to lift your leg, lean at an angle to place, etc.)
- Knowing color/type of loops for mechanical transfer
- Bed transfers
- Car transfers
- Body handling in emergency situation
- How to maneuver chair for transfers
- Transfers between surfaces of different heights or materials
- Getting a ride and getting into car
- Tying down chair into accessible van
- Emergency style transfer
- Which body part needs to go where to safely transfer
- Guarding for transfers

Other Mobility

- Bed mobility (how to perform, use of draw sheet, etc.)
- Turning
- Transportation use
- Tying down chair into accessible van
- Wheelchair skills (power and manual)
- Proper guarding during walking
- Use of walker
- Fall prevention
- Lifting, pulling, pushing techniques (body mechanics)
- Mechanics of moving person (so not lose balance when transferring)

Legal/Financial

- Managing funding
- Managing personal affairs (opening mail, filing bills, fill out checks, and other personal things)

- Use of fitness equipment (electrical stimulation bike, for example)
- Moving legs to minimize spasms

Other Medical/Health Issues

- Prevention of secondary complications
- Recognizing signs of autonomic dysreflexia (such as headache, fingers tightening, etc.)
- How to respond to an episode of autonomic dysreflexia
- Proper donning/doffing of TED hose, abdominal binder
- Avoiding e. coli or other infection (Don't touch open sore, etc.)
- Knowing all precautions
- Knowing all the things that can be a medical emergency
- Taking blood pressure
- How to manage orthostasis (low blood pressure related to positioning)
- Knowing medications and timing
- How to give you medicine
- Side effects (medicine for spasms can make you sleepy, for example)
- Hand hygiene and glove use
- Lymphedema wrapping
- Upper limb preservation
- Energy conservation (# transfers in a day, etc.)
- Checking toes to make sure not black and blue (blood circulation)
- Cardiac changes
- Aging with SCI

APPENDIX 6

Presentation Abstracts (Listed in Reverse Chronological Order)

Development of the TEAM Tool: An Assessment of Skills in Directing Care and Caregiving
(Poster Presented at ACRM 2017)

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Research Objectives: To develop a tool to assess the ability of people with tetraplegia (PWT) due to spinal cord injury (SCI) to direct their care and the ability of caregivers to provide assistance.

Design: Iterative process of separate focus groups of PWT, paid and unpaid caregivers, and SCI rehabilitation professionals, tool drafting, conference calls with subsets of focus group participants to review drafts, and tool revisions after each call.

Setting: Community (PWT and caregivers); Inpatient rehabilitation (professionals)

Participants: 26 people with chronic (≥ 1 year) tetraplegia due to SCI with ≥ 6 months experience directing caregivers; 16 caregivers (informal or hired) of PWT with ≥ 6 months experience providing care; 25 SCI professionals who train PWT and their caregivers during inpatient rehabilitation.

Interventions: Not applicable.

Main Outcome Measures: Teaching Effective Assistance Management (TEAM) Tool

Results: Key focus group themes included: assistance is needed for a wide variety of medical and non-medical tasks; effective communication, the ability to problem-solve, and the ability to prevent injury or complications are critical for successful care; each member of the care team (care director and caregiver) contributes to the team's success. The TEAM Tool allows assessments of direction of care and caregiving ability to be made for tasks in six domains: Preventing Complications, Mobility in Daily Life, Other Daily Activities, Communicating Effectively, Home and Community Living, and Managing Personnel. The scoring system includes subscales for Safety, Problem-Solving, and Communication. Separate scores are given for the care director (PWT), the caregiver, and the team.

Conclusions: The TEAM Tool is the first assessment tool designed to evaluate direction of care and caregiving skills. Pilot-testing is underway to refine the tool for clinical use.

Learning to Direct Care After Spinal Cord Injury

(Poster Presented at ACRM 2016)

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Objective: To better understand challenges faced and lessons learned by people with tetraplegia due to SCI as they become skilled in directing their own care in the community.

Design: Qualitative analysis of data acquired prospectively through focus groups.

Setting: Gathering of community-dwelling people with SCI.

Participants: Twenty-six people with chronic (≥ 1 year) tetraplegia resulting from traumatic or non-traumatic SCI who provide direction to caregivers on a daily basis as they assist with self-care and other activities.

Interventions: Not applicable.

Main Outcome Measures: Themes identified through content analysis.

Results: Challenges encountered when learning to direct one's care included: (1) difficulty engaging in direction of care training during inpatient rehabilitation because of denial or difficulty accepting long-term care needs; (2) overwhelming volume of information presented in a short time during inpatient rehabilitation; (3) differences in physical and other characteristics between the hospital setting and "the real world"; (4) not yet understanding their post-SCI body; (5) hesitance to criticize caregivers because of feelings of vulnerability, wanting to avoid nitpicking, and/or fear of retaliation; (6) lack of assistants who are knowledgeable about SCI. Participants stressed time, experience, paying attention to one's body (particularly for signs of complications), speaking with peers with SCI, communicating clearly, and learning when to let go and when to speak up as factors that helped them direct care more effectively.

Conclusions: The ability to direct one's care is a complex skill that is developed over time, and requires self-awareness, self-confidence, and strong communication skills. Efforts to prepare people with new SCI to direct care effectively should provide opportunities for real-world practice, cultivate awareness of one's body, address strategies for communicating effectively with caregivers, and provide opportunities to discuss direction of care with experienced peers.

Building Positive Working Relationships Between People with SCI and Caregivers

(Oral Presentation Given at ASCIP 2016)

Jeanne M. Zanca, PhD, MPT¹; John Morris, PhD²; Carol Gibson-Gill, MD³;
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Objective: To present suggestions for fostering positive interpersonal dynamics between people with spinal cord injury (SCI) and their caregivers identified in discussions with people with tetraplegia, caregivers, and SCI clinicians.

Design: Qualitative analysis of data acquired through focus groups.

Participants/Methods: Focus groups were conducted with people with tetraplegia due to SCI who have experience directing their care (n= 26), family and/or hired caregivers (n=13), and SCI clinicians (n=25) as part of a larger project whose objective was to create an assessment tool for direction of care/caregiving skills. Discussion topics included learning to direct and provide care, characteristics of good direction of care and caregiving, suggested topics for training and other related experiences. Recordings of the discussions were transcribed and imported into NVivo for coding by primary and secondary themes. Interpersonal dynamics emerged as a key theme. Subthemes that discuss suggestions for promoting positive working relationships between caregivers and people with SCI are presented here.

Results: Key suggestions included: (1) Set and document expectations early in a collaborative process that involves both the person with SCI and caregiver. (2) Explain not only WHAT needs to be done, but WHY to avoid the perception of being “picky” and to give respect to the contributions caregivers make to health and function. (3) Respect each other’s expertise. (4) Acknowledge when things don’t feel right so that a solution can be identified early. (5) Be flexible and open to collaboratively finding new ways of doing things. (6) Periodically step back and re-assess the big picture of how the dynamics feel to identify areas for improvement or strengths to cultivate. (7) Treat one another as you would like to be treated.

Conclusion: Interpersonal dynamics play a key role in the success or failure of the care experience. Through trial, error, and experience, people with SCI and their caregivers have identified strategies for promoting mutual respect and successful collaboration. Findings from this investigation will inform the development of consumer education materials to promote positive relationships.

Support: This research was supported by the Department of Defense Spinal Cord Injury Research Program under award number W81XWH-12-1-0553. Views and opinions of, and endorsements by, the authors do not reflect those of the US Army or the Department of Defense.

Direction of Care and Caregiver Training in Inpatient Rehabilitation

(Poster Presented at ASCIP 2015)

Jeanne M. Zanca, PhD, MPT
Kessler Foundation, West Orange, New Jersey

Objective: To aid the creation of outcome measures that address direction of care and caregiving skills by identifying topics discussed in direction of care and caregiver training in inpatient rehabilitation as well as methods used by clinicians to describe progress made during skill development.

Design: Qualitative analysis of data acquired through retrospective chart review.

Participants/Methods: Eight medical charts of acute rehabilitation inpatients with tetraplegia who were expected to require daily assistance from a caregiver after discharge were reviewed to identify statements related to direction of care and caregiver training. Content related to goals, topics discussed, and progress made were abstracted and imported into NVivo for coding by primary and secondary themes.

Results: Self-care, activities of daily living, equipment use, management and prevention of secondary complications, emergency preparedness, and management of medical conditions were among those topics discussed during patient and caregiver training in inpatient rehabilitation. Methods used by clinicians to characterize the ability of people with tetraplegia and/or their caregivers to direct or perform care tasks included the level of independence with which a task is performed or directed, quality (“good”, “fair”, “poor”) of task performance, accuracy (“correctness”) of task performance or knowledge demonstration, timing and/or frequency (compared to a pre-defined ideal), completeness, and extent to which further training is needed.

Conclusion: Clinicians address a wide array of topics with people with tetraplegia and their caregivers in the course of inpatient rehabilitation. Both qualitative and quantitative methods are used by clinicians to characterize level of skill in direction of care and caregiving task performance. Findings from this investigation will inform the development of items and rating scales for outcome measures of direction of care and caregiving skills. Such measures will facilitate team communications, discharge planning, and research demonstrating the importance of direction of care and caregiving skills to health and quality of life post-SCI.

Support: This research was supported by the Department of Defense Spinal Cord Injury Research Program under award number W81XWH-12-1-0553. Views and opinions of, and endorsements by the author do not reflect those of the US Army or the Department of Defense.

APPENDIX 7

Full Presentations

Development of the TEAM Tool: An Assessment of Skills in Directing Care and Caregiving

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INTRODUCTION AND OBJECTIVE

Assistance from others is critical to enable many people with tetraplegia to live successful and healthy lives in the community.

Direction-of-care and caregiving training are important parts of inpatient rehabilitation but are not addressed by current assessment tools

Potential benefits of an assessment tool for direction of care and caregiving skills include:

- 1) Improved communication among professionals and those being trained
- 2) Better preparation for discharge
- 3) Ability to examine connections between direction of care/caregiving ability and health and quality of life outcomes for people with SCI.

The objective of this project is to develop a tool to assess the ability of people with tetraplegia (PWT) due to spinal cord injury (SCI) to direct their care and the ability of caregivers to provide care.

TOOL DEVELOPMENT PROCESS

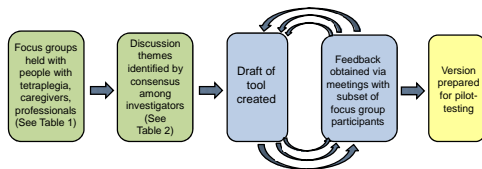


Table 1. Characteristics of Focus Group Participants*

	People with Tetraplegia	Caregivers	Clinicians**
n	26	16	25
Age in Years [Median (Range)]	50 (29-81)	59 (24-74)	40 (25-59)
Sex [% Male]	65	19	16
Ethnicity [%Hispanic]	8	6	0
Race [% White]	48	44	71
Years Post-Injury [Median (Range)]	20 (1-50)
Years of Caregiving Experience [Median (Range)]	...	9 (1-38)	...
Years of Inpatient SCI Rehabilitation Experience [Median (Range)]	8 (1-28)

*One person with tetraplegia and one clinician did not provide these data. **Disciplines included Occupational Therapy, Physical Therapy, Nursing (n = 7 per discipline), Social Work (n=2), Nutrition (n=1), and Medicine (n=1).

FEATURES OF THE TEACHING EFFECTIVE ASSISTANCE MANAGEMENT (TEAM) TOOL

Three parts (A, B, C) divided by type of tasks/skills being assessed:

Part A: Health and/or everyday functioning; typically trained during inpatient rehabilitation

Part B: Communication-related behaviors

Part C: More advanced home and community skills, as well as managing hired staff.

Provides an extensive list of areas in which help from an assistant might be needed.

2 Tasks are described using technical language when possible to facilitate discussion with people with tetraplegia and caregivers.

3 Scores are given for three aspects of task performance:

- Safety (Parts A and C)
- Problem-Solving (Parts A and C)
- Communication (Part B only)

Scores reflect ability to appropriately execute the specified aspect of task performance *without assistance* from the trainer (nurse, therapist, etc.)

4 Separate scores are given for the 'Care Director' (typically the person with tetraplegia), 'Caregiver', and 'Team' (Care Director and Caregiver working together)

- This scoring reflects that each member contributes to the success of the task and that the team has a synergy
- Separate scoring allows the tool to be used in cases where a caregiver is not available for training during inpatient rehabilitation (only Care Director is scored)

Table 2. Key Themes That Guided Tool Development

Care Dynamics	Caregivers assist with a wide variety of medical and non-medical tasks Each person with tetraplegia has unique needs and preferences Tasks related to prevention of complications are considered particularly important Success requires teamwork, good communication, flexibility, ability to problem-solve
Training Process	Many factors make training difficult (Short lengths of stay, trainees being overwhelmed, lack of readiness to learn, difficulty scheduling training with caregivers) Conveying the importance of a task for health and function motivates learners
Potential Uses of an Assessment Tool in Rehabilitation	Goal-setting Building confidence among those being trained Promoting conversations about difficult subjects (ability to provide care, willingness, interpersonal dynamics) Assessing readiness for discharge and addressing gaps in training

DISCUSSION

Limitations

- The version presented here is being pilot-tested and is not yet ready for use.
- The tool was designed in hard copy format to facilitate logistics of pilot-testing. Space constraints influenced the appearance and content of the tool.
- Focus groups to inform tool development took place at both civilian and veteran facilities, however pilot-testing took place in civilian facilities only.

Future Work

- Changes will be made in response to stakeholder feedback obtained from pilot testing.
- Funding will be sought to convert and pilot-test the tool in an electronic format
- Additional testing is needed to assess the utility of the tool as a method of quantifying skill level for purposes of outcomes measurement.

Conclusions

- The TEAM Tool is the first assessment tool designed to systematically evaluate direction of care and caregiving skills among people with tetraplegia and their caregivers.
- Insights shared by study participants have informed tool development and identified challenges to address in the direction-of-care/caregiving training process.



This research was supported by the Department of Defense Spinal Cord Injury Research Program under award number W81XWH-12-1-0553. Views and opinions of, and endorsements by the author do not reflect those of the US Army or the Department of Defense.

The Northern New Jersey Spinal Cord Injury System is supported by a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant 9050111 and 9050126). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this poster do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

Special thanks go to Elizabeth Gonzales, CCRP, Ashleigh Quinn, Tomicka McMillon, RN, BSN, Marina Moldavsky, and Joyce Williams, LCSW, MSCS for their assistance in implementing this project.

Collaborators:



Shepherd Center



Mount Sinai





Learning to Direct Care After Spinal Cord Injury

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INTRODUCTION AND OBJECTIVE

- Assistance from others is critical to enable people with substantial motor deficits due to tetraplegia to live successful and healthy lives in the community.
- The ability to instruct others in how to provide assistance (known as "direction of care") is important to ensure that needs are met and prevent complications. The process of learning to direct one's care typically begins in inpatient rehabilitation.
- Direction of care skills empower people with substantial physical limitations to have control over their care and environment and facilitate participation in activities of importance to them.

The objective of this analysis is to better understand challenges faced and lessons learned by people with tetraplegia due to spinal cord injury (SCI) as they become skilled in directing their own care.

METHODS

Context. These data were collected as part of a larger study whose aim is to create a tool to assess the ability of people with tetraplegia to direct their care and the ability of caregivers to provide appropriate assistance.

Participants. People with tetraplegia due to SCI who:

- (1) Had SCI for at least 1 year
- (2) Had at least six months experience directing caregivers on a regular basis

Data Collection Procedures:

- Focus groups took place at Kessler, Shepherd Center, and VANJHCS
- Discussion questions developed with input from all investigators
- Two hour discussions were facilitated by lead investigator (JZ)
- Discussion topics included:
 - Process of learning to direct care
 - Characteristics of good direction of care
 - Suggested topics for training people with tetraplegia how to direct care
 - Other experiences related to direction of care and working with caregivers
- Discussions were recorded and transcribed

Data Analysis:

- Transcripts were reviewed by three investigators
- Initial list of primary themes and subthemes identified by lead investigator, then reviewed by co-investigator who suggested additions and revisions
- Final list of themes determined by consensus
- Current analysis focuses on themes related to barriers and facilitators to learning to direct one's care

RESULTS

Challenges encountered when learning to direct care included:

1. Difficulty engaging in inpatient direction-of-care training due to denial of one's long-term needs.

"...The first two or three months that I was here I wasn't trying to hear about, 'You're going to have to get a suppository or you have to get catheter, or anything like that... I was like 'I'm going to get better, my spinal cord is going to heal in a couple months, I'm going to go hard in therapy and I'm going to be fine. I'm going to be running around, I'm not going to have to worry about this.'"

"They throw so much at you. It's a lot to remember. You can't even begin to imagine what life is going to be like when you get home."

3. Differences between the hospital setting and "the real world."

"When I came home I was like, 'oh how am I supposed to do this?' Because the way I was doing it was on the bed, and then transferring. But then when I got home it just doesn't quite work that way."

4. Not yet understanding one's post-SCI body.

"When you come out of here you're so raw, you have no idea. I think I only stayed here for two months, and it was such a shock, I was 24 years old, independent, just starting my life, and I had no idea...Then when you go home, how are you going to teach somebody if you don't know yourself?"

5. Hesitance to criticize caregivers because of feelings of vulnerability, wanting to avoid nitpicking, and/or fear of retaliation.

"How do you lie in bed in need of certain services, certain care, direct your employee? Now, how do you reprimand them and give them direction without worrying about retaliation, passive aggressive stuff? It's so tough."

6. Lack of assistants who are knowledgeable about SCI.

"A lot of the aides had no idea. They just thought that you had a broken bone or something like that. So, they didn't understand some of the neurological things that if you had an accident or you spasms or something like that—they thought that it was something that they were doing or they would kind of be hesitant trying to move you."

Factors that facilitated more effective direction of care included:

1. The experience that comes with time.

"I think the only way to do it is time and experience... Unfortunately, your bowels have to touch your urological equipment and you gotta get E. coli and you've got to get your urinary tract infection, you've got to get your first emergency room visit and stuff like that, and until that really happens you don't know."

2. Paying attention to your one's body and changes in it (particularly signs of complications).

"I know different kind of spasms, what's causing them. So knowing your body—I know I have different types of spasms. One might be from ...not taking my medication. Others might be from some kind of a pain."

3. Speaking with peers with SCI about their experiences.

"You see other quads, you talk about your problems, and you learn 'he's doing that, I'll try that...We'd all talk about similar issues, similar things that are going on with us...When I see other people, you can share information and you gain knowledge that way too."

4. Learning to communicate clearly and specifically what needs to be done and why.

"I explain to them I want the coffee here, not because I'm ...a dictator, but why it needs to be here. Because I can reach it, I'm more independent...So explaining to them why you need certain things, when you need them, where you need them, and how you need them."

5. Learning when to let go and when to speak up.

"I try my best not to complain as much, because then when you do complain then they take it a little more serious... So don't complain so much, but when it's serious, complain, when need to. Try to bite your tongue a little bit, but at the end of the day I try to do what I can to make myself happy and go on with my life."

Table. Characteristics of Focus Group Participants with Tetraplegia			
	Kessler	Shepherd	VANJHCS
n	9	8	9
Age in Years [Median (Range)]	44 (29-67)	45 (30-61)	59 (43-81)
Sex [% Male]	67	57	100
Ethnicity [%Hispanic]	11	0	11
Race [% Caucasian]	56	57	33
Years Post-Injury [Median (Range)]	16 (2-50)	20 (1-44)	21 (2-38)
Paid Hours of Care Received Per Week [Median (Range)]	37 (6-56)	35 (9-72)	36 (0-140)
Unpaid Hours of Care Received Per Week [Median (Range)]	10 (2-12)	12 (0-24)	24 (2-168)

DISCUSSION

Limitations

- Civilians (and/or caregivers of civilians) have greater representation in the overall sample; reported fewer hours of unpaid care than veterans
- Delays in receipt of transcripts made in-depth analysis more difficult for veteran-affiliated groups
- Greater discussion of interactions with paid caregivers than with family caregivers (other barriers/facilitators may be pertinent to those interactions)

Conclusions

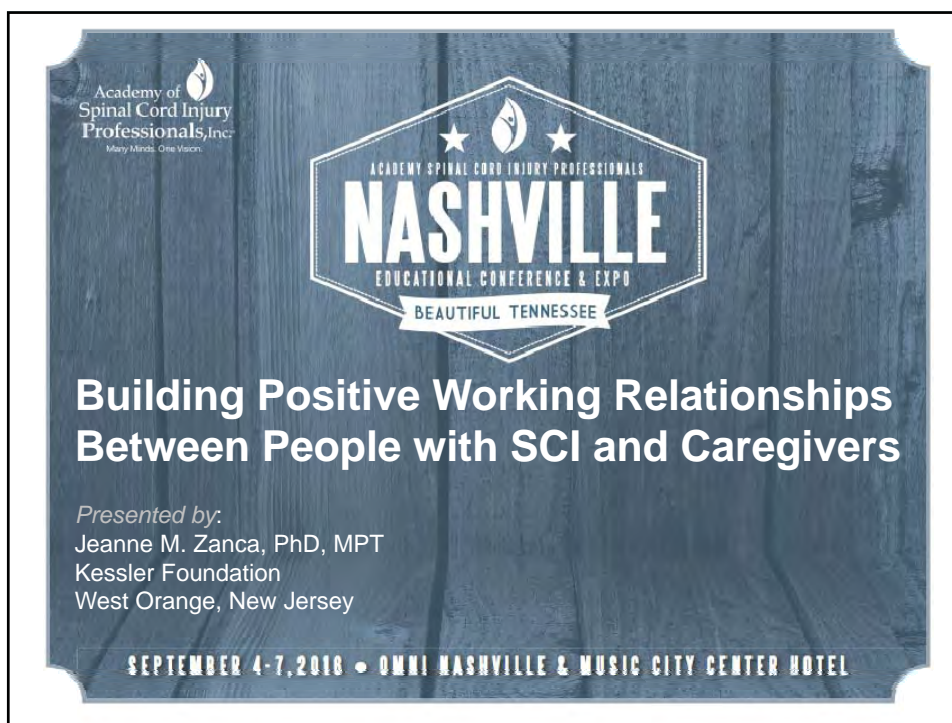
- The ability to direct one's care is a complex skill that is developed over time, and requires self-awareness, assertiveness, and strong communication skills.
- Efforts to prepare people with new SCI to direct care effectively should
 - (1) provide opportunities for real-world practice
 - (2) cultivate awareness of one's body,
 - (3) address strategies for communicating effectively with caregivers,
 - (4) encourage discussion of direction of care with experienced peers.



This research was supported by the Department of Defense Spinal Cord Injury Research Program under award number W81XWH-12-1-0503. Views and opinions of, and endorsements by the author do not reflect those of the US Army or the Department of Defense.

The Northern New Jersey Spinal Cord Injury System is supported by a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant 9050511-01-02). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this poster do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

Special thanks go to all our focus group participants for sharing their experiences, and to Elizabeth Gonzalez, CCRP, Ashleigh Quinn, Tomecka McMillan, RH, BSN, and Joyce Williams, LCSW, MSCS for their assistance in implementing the focus groups for this project.



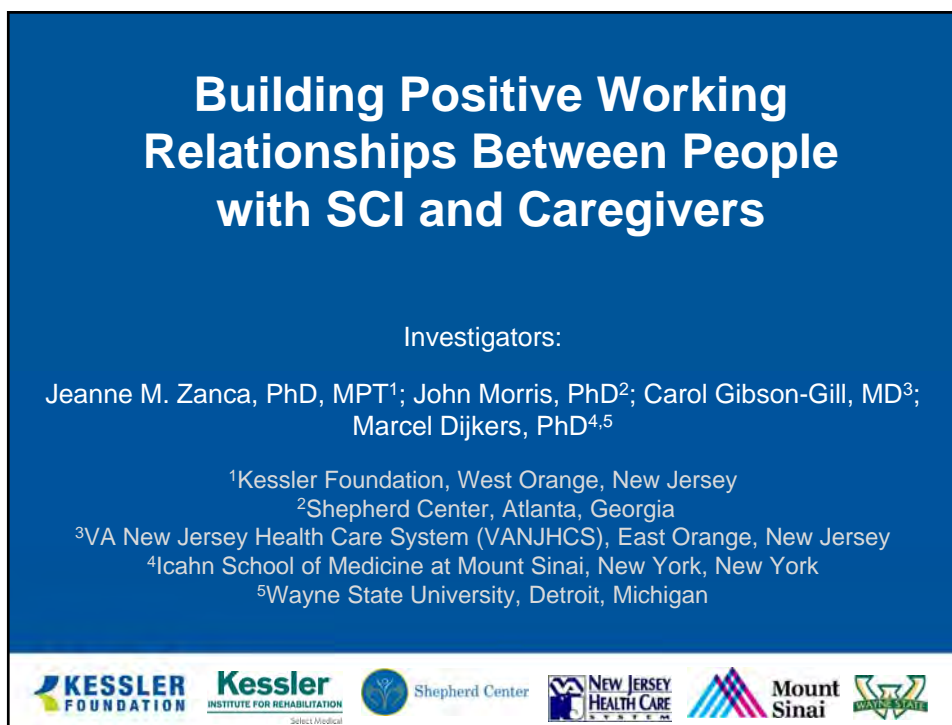
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**Building Positive Working Relationships
Between People with SCI and Caregivers**

Presented by:
Jeanne M. Zanca, PhD, MPT
Kessler Foundation
West Orange, New Jersey

SEPTEMBER 4-7, 2018 • OMNI NASHVILLE & MUSIC CITY CENTER HOTEL



**Building Positive Working
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Investigators:
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This research was supported by the **Department of Defense Spinal Cord Injury Research Program** under award number W81XWH-12-1-0553.

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Objective

- To present suggestions for fostering positive interpersonal dynamics between people with spinal cord injury (SCI) and their caregivers.



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Background

- People with tetraplegia due to SCI with significant loss of movement require assistance from others for most activities
- Average hours of care/day reported to range from 7 to 19, depending on the level of injury (Robinson-Whelen and Rintala 2003; Prince et al, 1995)
- Care may be provided by “informal” caregivers (spouse, other family, friends, etc.), paid caregivers, or a combination of both (Walker et al, 2015; Boschen et al 2005; Lucke et al 2004; Robinson-Whelen and Rintala 2003; Weitzenkamp et al 2002; Unalan et al 2001)
- Appropriate personal assistance is critical to maintain health and hygiene, prevent secondary complications, avoid institutionalization, and participate in family and community roles



Background

- Data collected in the context of a larger study whose aim is to create an assessment tool for direction of care and caregiving skills
- Participants frequently discussed importance of positive interpersonal dynamics with caregivers
- Analyses presented here focus on themes related to fostering healthy relationships



Methodology

- Focus groups were conducted with:
 - People with tetraplegia due to SCI (n = 26):
 - Injured for at least 1 year
 - Experience directing their care
 - Family and/or hired caregivers with at least six months experience providing care to a person with tetraplegia due to SCI (n = 16)
 - SCI clinicians involved in training people with tetraplegia and caregivers in inpatient rehabilitation (n = 25)



Methodology

- Focus groups took place at Kessler, Shepherd Center, and VANJHCS
- Discussion questions developed with input from all investigators
- Two hour discussions were facilitated by lead investigator (JZ)
- Discussion topics included:
 - Process of learning to direct and provide care
 - Characteristics of good direction of care and caregiving
 - Suggested topics for training
 - Other experiences related to direction of care and caregiving
- Discussions were recorded for later transcription



Methodology

- Transcripts compared with audio recordings and corrected as needed (notes and audio recordings were reviewed for VA-based groups due to delays in transcription process)
- Transcripts were reviewed by three investigators
- Initial list of primary themes and subthemes identified by lead investigator, then reviewed by co-investigator who suggested additions and revisions
- Final list of themes determined by consensus
- Themes related to promoting positive working relationships between caregivers and people with SCI are presented here in the form of suggestions for others



Participant Characteristics

People with Tetraplegia

	Kessler	Shepherd	VANJHCS
n	9	8	9
Age in Years [Median (Range)]	44 (29–67)	45 (30–61)	59 (43–81)
Sex [% Male]	67	57	100
Ethnicity [%Hispanic]	11	0	11
Race [% Caucasian]	56	57	33
Years Post-Injury [Median (Range)]	16 (2–50)	20 (1–44)	21 (2–38)
Paid Hours of Care Received Per Week [Median (Range)]	37 (6–56)	35 (9–72)	36 (0–140)
Unpaid Hours of Care Received Per Week [Median (Range)]	10 (2–12)	12 (0–24)	24 (2–168)



Participant Characteristics

People with Tetraplegia

	Kessler	Shepherd	VANJHCS
n	9	8	9
Age in Years [Median (Range)]	44 (29–67)	45 (30-61)	59 (43-81)
Sex [% Male]	67	57	100
Ethnicity [%Hispanic]	11	0	11
Race [% Caucasian]	56	57	33
Years Post-Injury [Median (Range)]	16 (2-50)	20 (1-44)	21 (2-38)
Paid Hours of Care Received Per Week [Median (Range)]	37 (6-56)	35 (9-72)	36 (0-140)
Unpaid Hours of Care Received Per Week [Median (Range)]	10 (2-12)	12 (0-24)	24 (2-168)



Participant Characteristics

Caregivers

	Kessler	Shepherd	VANJHCS
n	4	7	5
Age in Years [Median (Range)]	61 (24– 70)	52 (43-61)	63 (24-74)
Sex [% Male]	25	14	20
Ethnicity [%Hispanic]	25	0	0
Race [% Caucasian]	50	14	60
Years of Experience Providing Care [Median (Range)]	15 (3-25)	15 (1-35)	4 (2-38)
Hours of Care/Week Provided [Median (Range)]	30 (8-100)	48 (4-120)	40 (10-168)
% Hired (vs. Informal)	25	71	0



Participant Characteristics

Caregivers

	Kessler	Shepherd	VANJHCS
n	4	7	5
Age in Years [Median (Range)]	61 (24– 70)	52 (43-61)	63 (24-74)
Sex [% Male]	25	14	20
Ethnicity [%Hispanic]	25	0	0
Race [% Caucasian]	50	14	60
Years of Experience Providing Care [Median (Range)]	15 (3-25)	15 (1-35)	4 (2-38)
Hours of Care/Week Provided [Median (Range)]	30 (8-100)	48 (4-120)	40 (10-168)
% Hired (vs. Informal)	25	71	0



Participant Characteristics

SCI Clinicians

	Kessler	Shepherd	VANJHCS
n	9	9	7
Age in Years [Median (Range)]	39 (28-59)	41 (25-46)	41 (35-53)
Sex [% Male]	0	22	17
Ethnicity [%Hispanic]	0	0	0
Race [% Caucasian]	89	89	17
Discipline [%]			
Nursing	22	33	33
Occupational Therapy	33	33	17
Physical Therapy	33	33	17
Other	11	0	33
Years SCI Rehab Experience [Median (Range)]	12 (4-37)	8 (3-13)	10 (7-21)



Participant Characteristics

SCI Clinicians

	Kessler	Shepherd	VANJHCS
n	9	9	7
Age in Years [Median (Range)]	39 (28-59)	41 (25-46)	41 (35-53)
Sex [% Male]	0	22	17
Ethnicity [%Hispanic]	0	0	0
Race [% Caucasian]	89	89	17
Discipline [%]			
Nursing	22	33	33
Occupational Therapy	33	33	17
Physical Therapy	33	33	17
Other	11	0	33
Years SCI Rehab Experience [Median (Range)]	12 (4-37)	8 (3-13)	10 (7-21)



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Suggestions for Fostering Positive Interpersonal Relationships



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Suggestions

1. Set expectations early.
2. Explain not only WHAT needs to be done, but WHY.
3. Respect each other's expertise.
4. Be flexible and open to new ways of doing things.
5. Acknowledge when things don't feel right.
6. Step back and re-assess the big picture.
7. Treat one another as you would like to be treated.
8. Pick your battles.



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1. Set expectations early.

- Being “on the same page” is very important for a team to function well.
- Important to discuss:
 - What care tasks are needed and when
 - Schedule (including arrangements for each caregiver to have breaks during the day and days off)
 - Amount of notice needed for changes in schedule
 - “Ground Rules” about cell phone use, handling personal mail, reserving personal space for both parties, participation in social situations, etc.
 - Who has authority to direct care (person with SCI vs. spouse or others in household)



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1. Set expectations early.

- Ideally, both the person who requires assistance and the caregiver(s) should be involved in establishing expectations.
- Checklists, contracts, or other mechanisms for documenting expectations may be helpful.
 - Reminds everyone of what was discussed
 - Can make discussions less awkward later if something isn't being done as planned
 - Can help coordinate communications among caregivers when there are multiple people providing care over the day or week



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1. Set expectations early.

"It's also key that you put it all out in front--you're clear about what is expected. It's a benefit for both the person who's going to be the caregiver and yourself, to lay out exactly 'this is what I'm going to need,' 'this is what you have to do,' and be as detailed as possible, so that there are no surprises when you're actually doing this."

– Person with Tetraplegia



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1. Set expectations early.

“I am someone who is intensely private...I want my caregiver to have a very clear understanding. I want you to open [my mail], I might need you to pull it out and unfold it, but at that point, put it down, step away.”

– Person with Tetraplegia



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2. Explain not only WHAT needs to be done, but WHY.

- The needs and preferences of each person with tetraplegia are unique
- Doing things in a very specific way is important
 - For health or functioning (preventing infections, for example)
 - To respect the autonomy of the person with SCI
- Explaining WHY something needs to be done a certain way can:
 - Prevent perceptions of the recipient of care being “picky” or “bossy” by giving credibility to the request
 - Give value to caregivers’ efforts and convey respect for their contributions (and, in turn, enhance morale and motivation)
 - Increase the likelihood that things will be done the desired way



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2. Explain not only WHAT needs to be done, but WHY.

"I explain to them I want the coffee here, not because I'm ...a dictator, but why it needs to be here. Because I can reach it, I'm more independent...So explaining to them why you need certain things, when you need them, where you need them, and how you need them. Then they feel more like they're helping you, not that they're your servant."

– Person with Tetraplegia



3. Respect each other's expertise.

- Each member of the care team (person with tetraplegia and caregiver) brings something to the table.
 - People who live with SCI have requirements and preferences for how things should be done and often know the signs and symptoms that indicate something is wrong (spasticity, dysreflexia, etc.).
 - Caregivers may be in a position to observe things that the person with tetraplegia cannot see or feel.
- Share what you observe, and consider each other's perspectives when determining how to proceed.



3. Respect each other's expertise.

"I know different kind of spasms, what's causing them. So knowing your body—I know I have different types of spasms. One might be from ...not taking my medication. Others might be from some kind of a pain."

– Person with Tetraplegia

"After the appendix ruptured, they let him out of the hospital after several weeks. He received an impaction and we knew right away because we can tell how much is normal for his bowel movements and things like that."

– Caregiver



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4. Be flexible and open to new ways of doing things.

- There are many ways to accomplish tasks of daily living that are not necessarily known by medical professionals – bathing, turning, lotioning, massage, etc.
- Each person has different capabilities, which may influence how things are best done.
- Sometimes it takes trial and error by the person receiving care *and* the caregiver to find creative solutions to tasks and challenges.
- Listen to each other and consider each other's suggestions.



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4. Be flexible and open to new ways of doing things.

“A lot of times when you're a caregiver, it's a lot of trial and error and as long as the consumer you're working with isn't afraid to try things, well then—he's got a good thing going there.”

- Caregiver



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5. Acknowledge when things don't feel right.

- Explaining how to do something is not easy.
- Different people learn different ways.
- Everyone has misunderstandings sometimes.
- Watch for signs of uncertainty or frustration, which could mean something is not being communicated well.
- If something feels wrong, acknowledge it.
- Getting these issues out in the open early on can avoid creating bigger problems down the road.



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5. Acknowledge when things don't feel right.

"...You can say the same thing over, three different ways, but if that's not how they learn, you're not going to accomplish anything...If I direct something in a specific way and it's clear they're not grasping it, then I say 'How can I do this better? Like 'How can I help you help me?'"

- Person with Tetraplegia



6. Step back and re-assess the big picture.

- It can be easy to get caught up in the details of day-to-day care.
- Ask each other:
 - How did the day go for you?
 - What worked well? What could have been better?
 - Was the day frustrating or satisfying?
- Taking time to think about how things are going in general can help identify challenges and solutions that might not otherwise be found.



6. Step back and re-assess the big picture.

"I think first is respect the patient [person with SCI]. You know, being there. Listening to the patient [person with SCI]. And asking for feedback from them... 'So how was the day? What did you think needed to be different?'"

- Caregiver



7. Treat one other as you would like to be treated.

- Say "please" and "thank you."
- Use a kind tone of voice and respectful language.
- Be patient. Acknowledge that everyone has good days and bad days.
- Treating each other well builds and maintains a foundation of trust that is essential for navigating times when things don't go so well.



7. Treat one other as you would like to be treated.

"I think you have to treat the person that you're dealing with nicely. That's what it comes down to. Because if you treat somebody like a jerk it's going to come boomeranging right back at you. Either they're going to [give] poor care or are going to leave on you."

- Person with Tetraplegia

"I have an aide right now, we been together for a while, there's little idiosyncrasies that come up once in a while that drive me crazy, and I'm sure I do the same thing to her. But you have to be flexible, I think, no matter who it is."

- Person with Tetraplegia



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8. Pick your battles.

- Even with instructions, caregivers don't always do what you would like them to do.
- Too much criticism may damage the relationship or cause your caregiver to leave.
- Decide what you can live with and what you can't.
- Focus your feedback on what is most important.



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8. Pick your battles.

"I try my best not to complain as much, because then when you do complain then they take it a little more serious...So don't complain so much, but when it's serious, complain, when need be. Try to bite your tongue a little bit, but at the end of the day I try to do what I can to make myself happy and go on with my life."

- Person with Tetraplegia



Discussion

- Limitations
 - Focus group question guide not developed with relationship-building as a primary focus
 - Greater depth of feedback might have been forthcoming with different questions
 - People with tetraplegia often discussed interactions with paid caregivers
 - Other suggestions may have emerged if focus was placed on informal caregiver relationships



Discussion

- Limitations (continued)
 - Civilians (and/or caregivers of civilians) have greater representation in the overall sample
 - Delays in transcription made in-depth analysis more difficult for veteran-affiliated groups
 - Differences between veteran and civilian-derived feedback were not specifically examined in this analysis (but will be assessed in the future)



Discussion

- Key Ideas
 - Strong interpersonal skills are key to successful direction of care and caregiving
 - Working successfully with caregivers requires mutual respect and a delicate balance of assertiveness and flexibility
 - Much is learned through trial and error



Discussion

- Application to Practice
 - Important to devote time and effort to developing interpersonal skills
 - Suggestions presented here could inform development of education materials and programs for people with tetraplegia and caregivers
 - Peer-mentoring by experienced people with tetraplegia and/or caregivers likely plays an important role in interpersonal skill development and problem-solving



Thank You

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Building Positive Working Relationships Between People with SCI and Caregivers

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ACADEMY OF SPINAL CORD INJURY PROFESSIONALS



Direction of Care and Caregiver Training in Inpatient Rehabilitation

Jeanne M. Zanca, PhD, MPT

Spinal Cord Injury Research/Outcomes & Assessment Research • Kessler Foundation • West Orange, New Jersey



INTRODUCTION AND OBJECTIVE

- Assistance from others is critical to enable people with substantial motor deficits due to tetraplegia to live successful and healthy lives in the community.
- Training in direction of care and caregiving skills are important parts of inpatient rehabilitation but are not addressed in current rehabilitation outcome measures.
- Assessment tools for direction of care and caregiving skills would aid: (1) team communication, (2) discharge planning, (3) research to demonstrate connections between the quality of direction of care/caregiving and health and quality of life for people with SCI.

The objective of this analysis is to identify topics discussed during direction of care and caregiver training in inpatient rehabilitation, as well as methods used by clinicians to describe progress made in skill development.

This analysis will inform the development of an assessment tool for direction of care/caregiving skills.

METHODS

Participant inclusion criteria and recruitment. All procedures were approved by the Kessler Foundation IRB prior to implementation. A database of participants in the Northern New Jersey Spinal Cord Injury System was searched to identify those who:

- Had C1-6 motor complete (AIS A or B) tetraplegia
- Were discharged to home from inpatient rehabilitation
- Were expected to require daily assistance from caregivers for self-care or other activities (indicated by Functional Independence Measure™ discharge scores of 3 or less for at least 3 of the following 5 activities: Grooming, Bathing, Dressing – Lower Body, Dressing – Upper Body, Toileting)

Participants who met these criteria were contacted by phone to describe the investigation, answer questions, and obtain informed consent to participate.

Data abstraction and synthesis. Inpatient rehabilitation medical chart documentation (assessments, goal sheets, progress notes, discharge summaries, etc.) was obtained and reviewed to identify statements related to direction of care and caregiver training. Content about direction of care or caregiver performance goals, topics discussed during training, and progress made were abstracted and imported into NVivo™ to facilitate coding of abstracted text. Text was reviewed to develop a list of topics addressed in training interactions, and to identify themes for the methods by which clinicians describe direction of care and caregiving ability.



This research was supported by the Department of Defense Spinal Cord Injury Research Program under award number W81XWH-12-1-0553. Views and opinions of, and endorsements by the author do not reflect those of the US Army or the Department of Defense.

The Northern New Jersey Spinal Cord Injury System is supported by a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant 90SI011-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this poster do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

RESULTS

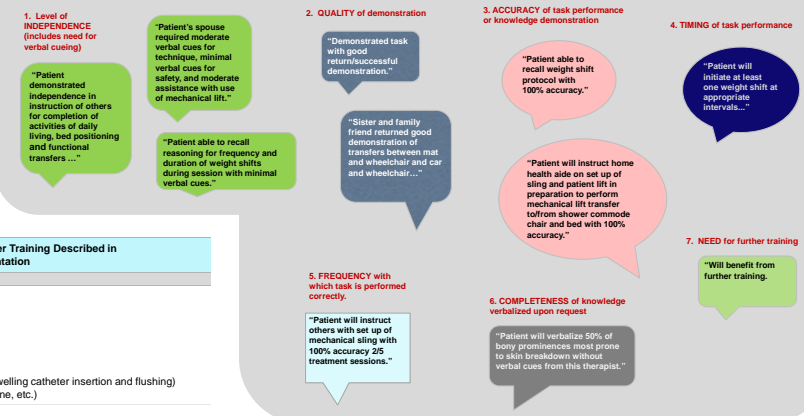
Table 1. Characteristics of Patients Whose Charts Were Reviewed (n = 8)

Age at Injury (Median [Range])	54 (24 – 62)
Gender (% Male)	88
Etiology of SCI (n)	
Vehicular Accident	4
Fall	2
Sport Injury	1
Other	1
Level of Injury (n)	
C3	1
C4	3
C5	2
C6	2
Length of Stay in Rehabilitation, days (Median [Range])	80 (55 – 138)

Table 2. Topics of Direction of Care and/or Caregiver Training Described in Inpatient Rehabilitation Documentation

Main Topic	Subtopics
Activities of Daily Living	Eating/feeding (setup of items, assisted feeding, etc.) Bathing (in bed, in shower chair) Dressing upper and lower body Bed mobility Transfers (to bed, shower chair, etc.) Bowel management (digital stimulation, etc.) Bladder management (intermittent catheterization, indwelling catheter insertion and flushing) Electronic ADLs (setup of a tablet computer or cell phone, etc.)
Features and Use of Durable Medical Equipment and Assistive Devices	Shower commode chair Mechanical lift (sling setup, operation to perform transfer) Manual wheelchair (use of manual tilt-in-space, wheel locks, traversing curbs/ramps, etc.) Power wheelchair (driving on and off wheelchair lift, using attendant drive, keeping batteries charged, etc.) Hospital bed Specialty mattresses (rotating, alternating pressure, etc.) Positioning devices (such as splints, pads, wheelchair seating components) Ventilator (including management of lines during transfers) Assisted cough/suctioning devices
Management and Prevention of Secondary Complications	Pain management techniques Skin integrity preservation (skin inspection, skin care, weight-shifting, positioning, etc.) Wound care Contracture prevention (passive range of motion, use of positioning devices, etc.) Autonomic dysreflexia (signs, symptoms, interventions) Orthostatic hypotension (signs, symptoms, interventions) Respiratory care (swallowing techniques to avoid aspiration, assisted cough, etc.) Shoulder preservation techniques
Emergency Preparedness	Emergency ventilation (using manual bag technique) Evacuation methods (chair bumping, two person lift)
Other Issues	Dietary restrictions Medication management Fall prevention strategies Home exercise program Precautions (spinal or other) Personal attendant recruitment and management (hiring, firing, scheduling, etc.)

Figure. Descriptors of Direction of Care/Caregiving Ability Used in Progress Notes or Goal Sheets



DISCUSSION

- Clinicians address a wide array of topics with persons with tetraplegia and their caregivers in the course of inpatient rehabilitation.
- Both qualitative and quantitative methods are used by clinicians to characterize level of skill in direction of care and caregiving task performance.
- Findings from this investigation will inform the development of items and rating scales for outcome measures of direction of care and caregiving skills.
- Such measures will facilitate team communications, discharge planning, and research demonstrating the importance of direction of care and caregiving skills to health and quality of life post-SCI.

Special thanks go Amanda Botticello, PhD, MPH, G. Melissa Garcia, and Ashleigh Quinn for their assistance with this project.

EDUCATIONAL CONFERENCE & EXPO 2015

APPENDIX 8
Newsletter Article

CAREGIVER CORNER: Tips for Establishing a Successful Caregiving Relationship

Jeanne Zanca

Conducting research on caregiving gives me the opportunity to speak with people who have spinal cord injury, and the family members and hired caregivers who assist them on a regular basis. Much discussion centers on the importance of the caregiving relationship and the interpersonal dynamics that can drive success or failure. The following wisdom they've shared with me may be helpful to others:


1 Set expectations early. Being “on the same page” is very important for a team to function well. From the beginning, be specific about: what care tasks are needed and when, caregiving schedule (including arrangements for time off—particularly for family caregivers), how much notice is needed for changes in schedule, “ground rules” about cell phone use, handling of personal mail, reserving personal space for both parties, and any other topics of concern. The person requiring assistance and the caregiver should share in setting expectations that are mutually agreed upon. Checklists, contracts, or other mechanisms for documenting these expectations can be helpful reminders. Being able to refer to a previously agreed upon list can make discussions less awkward later if something isn't happening as planned.

2 Respect each other's expertise. Each member of the care team brings something to the table. Those who have lived with disabilities for awhile have learned what works well for them and what doesn't, and which subtle signs and symptoms may mean something is wrong. Caregivers may be in a better position to observe certain things the person with the disability cannot see. Pay attention and share what you observe. Being open to new ways of doing things can help both of you to be successful.

3 Step back and re-assess the big picture. Ask each other: how did the day go for you? What worked well? What could have been better? It's easy to get caught up in the details of day-to-day care. Taking some time to think about how things are going in general can help identify challenges and solutions that may improve many aspects of the care experience.

4 Explain not only WHAT needs to be done, but WHY. Handling supplies correctly can prevent infections that could be deadly. Where an item is put away can make the difference between a person with a disability doing something independently and being stranded. Explaining WHY something needs to be done a certain way can prevent perceptions of being “picky” or “bossy”. Explaining why something is important gives value to caregivers' efforts, conveys respect for their contributions, and increases the likelihood that things will be done the “right” way.

5 Acknowledge when things don't feel right. Explaining how to do something is not easy. People learn in different ways and everyone has misunderstandings at times. Watch each other for signs of uncertainty or frustration (furrowed brows, sighs, negative language or tone of voice). If something feels wrong, acknowledge it. A person directing care could say, “It seems like I am not explaining this well—how can I do this better?” A caregiver could say, “I don't feel like I am doing this right—can you tell me what I should be doing differently?” Getting these issues out in the open early on can avoid creating bigger problems.

6 Treat each other as you would like to be treated. Say please and thank you. Use a kind tone of voice and respectful language. Be patient. Acknowledge that everyone has good days and bad days. By treating each other well, the good days will far outnumber the bad. 

APPENDIX 9

Teaching Effective Assistance Management (“TEAM”) Tool

Version Used for Piloting

Teaching Effective Assistance Management (TEAM) Tool [v. 4/12/17] - Page 1 of 4

Clinician Initials: _____ Discipline (circle): PT OT NRSNG

Date Completed: _____ Period: Admission Mid-stay D/C

TASKS – Part A

Care Director

& Caregiver

= Team

Initials: _____

Initials (or relationship): _____

Safety Problem-Solving

Safety Problem-Solving

Safety Problem-Solving

N/A

Preventing Complications (Domain 1)

- Maintaining Breathing ☐
- Managing Blood Pressure ☐
- Responding to Autonomic Dysreflexia ☐
- Properly Cleaning and Caring for Skin ☐
- Detecting/Responding to Signs of Skin Problems ☐
- Emptying Bowels Regularly ☐
- Emptying Bladder Regularly ☐
- Using Medications as Prescribed ☐
- Taking Precautions Against Infection ☐
- Proper Body Positioning in Bed ☐
- Proper Body Positioning in Wheelchair ☐
- Performing Range of Motion ☐

(Other) _____

Sum of scores for this domain ÷ # of tasks scored

= PREVENTING COMPLICATIONS SCORE

Mobility in Daily Life (Domain 2)

- Transfers Between Level Surfaces ☐
- Transfers Between Uneven Surfaces ☐
- Emergency Transfers ☐
- Moving Around in Bed ☐
- Mobility (Walking or Wheelchair) on Flat Surfaces ☐
- Mobility (Walking or Wheelchair) on Uneven Surfaces ☐
- Managing Wheelchair Parts ☐

(Other) _____

Sum of scores for this domain ÷ # of tasks scored

= MOBILITY SCORE

Other Daily Activities (Domain 3)

- Eating and Drinking ☐
- Bathing ☐
- Grooming ☐
- Dressing ☐

(Other) _____

Sum of scores for this domain ÷ # of tasks scored

= OTHER DAILY ACTIVITIES SCORE

Sum of task scores in domains 1-3 ÷ # tasks scored

= OVERALL SCORE for Part A

TASKS – Part B		Care Director	& Caregiver	= Team
N/A		Communication	Communication	Communication
Communicating Effectively (Domain 4)				
Using Appropriate Language	<input type="checkbox"/>			
Using Appropriate Tone of Voice	<input type="checkbox"/>			
Detecting/Responding to Misunderstanding or Uncertainty	<input type="checkbox"/>			
Rephrasing or Changing Instructions When Needed	<input type="checkbox"/>			
Speaking Up for Needs or Concerns	<input type="checkbox"/>			
Providing Helpful Feedback	<input type="checkbox"/>			
Being an Active Listener	<input type="checkbox"/>			
(Other)				
Sum of scores for this domain ÷ # of tasks scored		____ ÷ ____	____ ÷ ____	____ ÷ ____
= COMMUNICATION SCORE (OVERALL SCORE Part B)				

Scale Definitions and Scoring Criteria for Parts A and C:

For each scale, select the score that best reflects the abilities of the person (care director or caregiver) or team (care director and caregiver working together), considering all behaviors observed over the **past week**. If performance varied during this period, select the score that best represents the **CURRENT** abilities of the care director, caregiver, or team. Mark "N/A" if a task does not require assistance from a caregiver or is not medically or functionally relevant to the person with tetraplegia.

Safety Scale: Addresses ability to direct or perform a care task in a manner that prevents illness or injury (physical, emotional, or financial) to the person receiving assistance or his/her caregiver.

Safety Scoring: How much of the care direction/caregiving is performed safely *without assistance* from the trainer?

1. None – Requires assistance from the trainer to direct or perform all of this task safely
2. Some – Able to direct or perform some of this task safely without assistance from trainer
3. Most – Able to direct or perform most of this task safely without assistance from trainer
4. All – Able to direct or perform all of this task safely without assistance from the trainer

Problem-Solving Scale: Relates to the ability to adjust how a task is directed or performed in response to unusual or challenging circumstances to maintain safety and/or increase efficiency.

Problem-Solving Scoring: How much of the problem-solving process can be done *without assistance* from the trainer?

1. None – Requires complete assistance from trainer to identify problems and implement solutions
2. Some – Able to identify problems, requires assistance from trainer to identify and implement solutions
3. Most – Able to identify both problems and appropriate solutions but requires assistance from trainer to implement solutions
4. All – Able to identify problems and appropriate solutions, and can implement solutions without assistance from trainer

Scoring Criteria for Part B:

Communication Scale: Relates to the ability of the care director and caregiver to communicate effectively and appropriately with one another.

Communication Scoring: How much of the time is communication occurring in an appropriate manner *without assistance* from the trainer?

1. None – Unable to communicate effectively without assistance from trainer
2. Some – Able to communicate effectively *some* of the time without assistance from trainer
3. Most – Able to communicate effectively *most* of the time without assistance from trainer
4. All – Able to communicate effectively *all* of the time without assistance from trainer

TASKS – Part C (OPTIONAL for Pilot-Testing)		<u>Care Director</u>		<u>& Caregiver</u>		<u>= Team</u>	
		Safety	Problem-Solving	Safety	Problem-Solving	Safety	Problem-Solving
Home and Community Living (Domain 5)		N/A					
	Child Care (if applicable) <input type="checkbox"/>						
	Pet Care (if applicable) <input type="checkbox"/>						
	Maintaining a Clean and Healthy Home Environment <input type="checkbox"/>						
	Food Preparation <input type="checkbox"/>						
	Phone and Computer Access <input type="checkbox"/>						
	Managing Legal/Financial Documents & Affairs <input type="checkbox"/>						
	Maintaining Stock of Supplies <input type="checkbox"/>						
	Maintaining Equipment <input type="checkbox"/>						
	Transportation and Travel Planning <input type="checkbox"/>						
	Work, School, or Leisure Activities <input type="checkbox"/>						
	Performing Exercises for Strength or Fitness <input type="checkbox"/>						
	Facilitating Intimate Relationships <input type="checkbox"/>						
	Accessing Resources When Needed <input type="checkbox"/>						
	_____ (Other)						
	Sum of scores for this domain ÷ # of tasks scored	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____
	= HOME/COMMUNITY SCORE						
Managing Personnel (Domain 6)							
	Recruiting and Interviewing <input type="checkbox"/>						
	Establishing Expectations and Policies <input type="checkbox"/>						
	Coordinating Coverage and Schedules <input type="checkbox"/>						
	Transitioning to New Staff as Needed <input type="checkbox"/>						
	_____ (Other)						
	Sum of scores for this domain ÷ # of tasks scored	____ ÷ ____	____ ÷ ____				
	= MANAGEMENT SCORE						
	Sum of task scores in domains 5-6 ÷ # tasks scored	____ ÷ ____	____ ÷ ____				
	= OVERALL SCORE for Part C						

Do Not Score “Managing Personnel” Items in These Columns

These items will be scored only for the Care Director.

Use the HOME/COMMUNITY SCORE for Domain 5 as the OVERALL SCORE for Part C for the Caregiver and the Team.

Share your feedback!

Please use the space below (or email – see below) to note general comments or any difficulties you encountered in using the TEAM Tool. **When in doubt, fill out the form based on what feels most right to you and comment below about what you were uncertain about.** These could include difficulties deciding on a score, tasks that are not listed, areas where more guidance or clarity is needed in the instructions, etc. ANY ideas you may have for improving the content, format, or use of the TEAM Tool itself or the Instruction Manual are welcome.

For questions about the TEAM Tool or the study in general, please contact:

Kehinde Cole

Research Assistant, Spinal Cord Injury Research, Kessler Foundation
Phone: 973-243-6985 Email: kcole@kesslerfoundation.org

(Kehinde is in regular contact with Jeanne Zanca and can relay questions to her as needed.)

Thank you for your help!

Please return this form to the designated location for collection by the study team.

Appendix 10

Teaching Effective Assistance Management (“TEAM”) Tool Instruction Guide

Version Used for Piloting

***Teaching Effective Assistance Management
(TEAM) Tool***

Instruction Manual

Version Date 8/17/2016



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The creation of the TEAM Tool and Instruction Manual was supported by the Department of Defense Spinal Cord Injury Research Program under award number W81XWH-12-1-0553. Views and opinions of, and endorsements by, the authors do not reflect those of the US Army or the Department of Defense.

Special thanks are given to all members of the research team, our clinical colleagues, and to the organizations whose collaboration made this project possible.

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1. Overview of the TEAM Tool

The TEAM Tool provides information on the ability of people with tetraplegia due to spinal cord injury to appropriately direct their care and on the ability of caregivers to provide appropriate assistance. The TEAM Tool is completed based on observations of behavior that rehabilitation experts make in the process of training people with tetraplegia and their caregivers in direction of care and caregiving skills.

The TEAM Tool is designed to provide a comprehensive, high-level view of direction of care and caregiving ability. It is intended to complement, not replace, existing medical record documentation and other outcome measures that discuss the functional status of the person with tetraplegia or describe the specific content of training.

2. Background

Depending on the severity of the injury, people with tetraplegia due to spinal cord injury may require help from others to complete daily activities such as washing, moving from bed to chair, preparing food, and other important tasks. Appropriate assistance is critical to enable people with tetraplegia to participate in life activities and to prevent many of the health complications that can result from tetraplegia, such as pressure injury, pneumonia, and urinary tract infections.

Family members are often involved in providing care to people with tetraplegia. People with tetraplegia may also receive care from paid caregivers who are not nurses or otherwise formally trained in how to care for someone with tetraplegia. In order for people with tetraplegia to get the best possible care at home (rather than having to stay in a hospital or nursing home) it is important that they be able to tell someone when they need care and what needs to be done to help them (referred to as “direction of care”). It is also important that family members or others who are providing care to someone with tetraplegia learn how to properly perform these care tasks.

The process of learning to direct and provide care usually begins in acute inpatient rehabilitation. Clinicians and other rehabilitation professionals provide instruction about SCI and its consequences as well as hands-on training in directing care and providing assistance in tasks such as bowel and bladder care, transfers, bathing, range-of-motion exercises, and other activities. Ideally, people with tetraplegia and their caregivers are offered opportunities to practice directing and providing care, and receive feedback from rehabilitation professionals on their performance. Learning direction of care and caregiving skills continues after discharge as people with tetraplegia and their families continue rehabilitation in an outpatient setting and gain experience in the community.

While training in direction of care and caregiving is an important part of inpatient rehabilitation, current assessment tools and outcome measures provide no information on these skills. Commonly-used tools such as the Functional Independence Measure provide scores that are based on the level of independence of the person with tetraplegia. For skills that pertain to physical activity, such as transfers, these tools do not differentiate individuals who are actively engaged and in control of the task via verbal direction from those that are not participating in any way. Similarly, the quality of the assistance provided by the caregiver is not considered in the scoring of these tools. As a result, the rehabilitation field does not have a systematic (well-defined and consistent) way of describing how well someone can direct or provide care.

3. Anticipated Benefits of Using the TEAM Tool

The TEAM Tool is expected to enhance rehabilitation care by:

- Helping to identify training goals
- Documenting improvements in direction of care and caregiving skills over time, to provide justification for ongoing rehabilitation and to build confidence among those being trained
- Promoting conversations about difficult subjects such as care needs, willingness and ability of loved ones to provide care, interpersonal dynamics, etc.
- Facilitating discharge planning by helping clinicians assess and discuss readiness for discharge, identify areas in need of further training to prepare for discharge, etc.

The TEAM Tool is expected to enhance program evaluation and research by:

- Demonstrating the extent to which training programs improve direction of care and caregiving skills
- Facilitating assessment of relationships between direction of care/caregiving ability and important outcomes (such as complications, rehospitalizations, cost of care, and well-being)

4. Key Terms

Care director typically refers to the person with tetraplegia who is being trained to verbally instruct others in how to provide assistance. In cases where a person with tetraplegia is not being trained to direct care due to severe cognitive impairments or other issues, a family member or other responsible party may be trained to direct other caregivers (such as hired aides). In such cases, the responsible party is considered the care director.

Caregiver refers to a person who is being trained to provide assistance to the person with tetraplegia. The term “caregiver” is used in a broad sense, and may refer to paid or unpaid caregivers, including family members, friends, or staff that is hired privately or provided through an agency.

Team refers to the care director and caregiver working together as a unit. Because the dynamics between specific people are unique, each combination of care director and caregiver is its own “team.”

Trainer refers to a clinician, rehabilitation professional, or other “expert” (such as an experienced peer educator) who provides training in direction of care and caregiving skills in a rehabilitation context.

Task refers to an activity or (more commonly) a set of activities related to a particular objective (such as proper body positioning) or area of functioning (such as eating and drinking). Each person with tetraplegia has a unique combination of needs and preferences. Therefore, the specific tasks to be performed will vary from person to person. Other forms of documentation, such as the medical record or checklists for caregivers, can provide detail on the specific tasks to be performed for a particular person with tetraplegia. The types of activities included in each task (the “scope” of the task) is defined in Section 6 below.

Scale refers to a way of “measuring” a particular aspect of care direction and/or caregiving performance. The TEAM Tool includes three scales: *Safety*, *Problem-Solving*, and *Communication*. Because these scales represent distinct concepts, scores are calculated separately for each scale using different scoring criteria.

Domain refers to a collection of tasks that relate to a larger goal or activity. The TEAM Tool provides information on six domains: Preventing Complications, Mobility in Daily Life, Other Daily Activities, Communicating Effectively, Home and Community Living, and Managing Personnel.

Domain Score refers to a score that is calculated within a particular domain, based on scores for all applicable tasks within that domain. Domain Scores are calculated separately for the Safety, Problem-Solving, and Communication scales.

Overall Score is calculated for each part (A, B, C) of the TEAM tool based on *all* the scores recorded for the tasks listed within a particular part (A, B, or C) of the form. Overall scores are calculated separately for the Safety, Problem-Solving, and Communication scales.

5. Structure of the TEAM Tool

Listing of Tasks

The TEAM Tool consists of three parts, organized by the nature of the tasks included in each part.

- **Part A** focuses on tasks that are fundamental to health and/or everyday functioning for which direction of care/caregiving training typically begins in an inpatient setting.
- **Part B** addresses communication-related behaviors that are observed by trainers as people with tetraplegia and their caregivers practice direction of care or providing care during training.
- **Part C** addresses more advanced skills related to maintaining one’s home, participating in community activities, and managing hired staff (if applicable). The tasks in Part C are included because they are considered important to people with tetraplegia and are needed for success in community life on the long-term. However, depending on the care setting, these areas may not be addressed in inpatient rehabilitation. Training may occur in outpatient rehabilitation in the context of other programs offered post-discharge. These advanced skills are therefore placed in a separate section of the TEAM Tool, but may be scored by inpatient trainers if they are addressed in training.

Separate Scoring for Care Director, Caregiver, and Team

Within each part of the TEAM Tool, scores are given separately for the care director, caregiver, and for the team (care director and caregiver working together). This approach to score assignment is designed to reflect that the success of a caregiving experience involves contributions from both members of the care team, who may differ in their levels of ability. This approach also provides flexibility, allowing the TEAM Tool to be utilized with the person with tetraplegia who is receiving training even if the caregiver has not yet been identified or is unable to attend training.

6. Scope of Tasks

For all domains, an “other” field is available on the form to provide trainers the option of adding another task that is relevant to the person with tetraplegia but is not already listed.

Part A

Domain 1. Preventing Complications

1. **Maintaining Breathing.** Includes ability to keep ventilator fully powered, properly maintained, and functioning at the correct settings as well as implementing emergency measures in case of a ventilator failure (including using manual bagging to maintain breathing and contacting appropriate people for help). Also includes suctioning, assisted coughs, tracheostomy care, adherence to swallowing-related precautions, and other measures taken to prevent secretions or food/liquids from interfering with breathing. May include use of supplemental oxygen if prescribed.
2. **Managing Blood Pressure.** Includes any actions taken to prevent a problematic drop or increase in blood pressure. Such actions may include use of stockings, abdominal binders, or other aids to help maintain pressure; medications to manage blood pressure; care with position changes to avoid sudden drop in blood pressure, and other actions.
3. **Responding to Autonomic Dysreflexia.** Includes recognizing signs of autonomic dysreflexia, taking actions to stop the dysreflexia (sitting up, emptying bladder, loosening clothing, using medication, etc.), and seeking emergency assistance if needed.
4. **Properly Cleaning and Caring for Skin.** Includes appropriate cleaning/rinsing of skin via a shower or bed bath, thoroughly drying the skin, applying lotion, handling the skin gently to avoid irritation or damage, and other actions needed to ensure skin remains clean, dry, and free of injury.
5. **Detecting/Responding to Signs of Skin Problems.** Includes inspecting skin in a manner that would allow signs of skin damage to be seen (such as using appropriate lighting, looking at all areas at risk), identifying areas that suggest a problem may be developing (such as pressure injury), and identifying appropriate actions to take to respond to what is found during inspection (adjusting sitting time or frequency of repositioning, contacting physician, etc.).
6. **Emptying Bowels Regularly.** Includes implementation of the prescribed bowel program. This includes use of medications or supplements, enemas or mini-enemas, suppositories, stimulation with one’s finger or a device, and other actions required so that all stool is removed from the bowel. Also includes correct assessment of when bowels are empty and performance of bowel emptying techniques with appropriate hand hygiene/glove use, and in a manner that reduces the likelihood of injuring the anus, rectum, or other bowel structures. May include proper colostomy use if

applicable. Also includes ability to identify when a bowel problem may require further intervention by a physician or other health care professional.

7. Emptying Bladder Regularly. Includes implementation of all actions required to ensure that the bladder is emptied completely and regularly. Includes proper hand hygiene, glove use, cleansing of skin in the areas where bladder emptying is occurring, and handling of supplies to prevent infection. Also includes correct use of bladder medications, catheters, physical techniques to induce urination (such as applying pressure), as prescribed. Also includes ability to identify when intervention by a physician or other health care professional may be required to address a possible infection or other issue (as indicated by the amount, odor, color, cloudiness of urine).
8. Using Medications as Prescribed. Pertains to taking medications at appropriate times and dosages, including ability to identify potential side effects and take action to follow-up on medication-related issues.
9. Taking Precautions Against Infection. Includes actions taken to avoid infection in any part of the body. Includes proper hand hygiene, cleaning or sanitizing of equipment that could spread infection (such as leg bags), appropriate handling and storage of equipment, etc. *Note: This task may overlap with others where proper execution of the task includes steps to prevent infection (such as maintaining breathing, emptying bladder regularly). Behaviors that relate both to infection control and to the performance of another task may be considered in the scoring of both tasks.*
10. Proper Body Positioning in Bed. Includes both static positioning in bed and turning techniques. May include supporting shoulders to avoid dislocation, preserving tightness in hands when needed for grasping objects (tenodesis), positioning body to avoid excessive pressure, ensuring ability to reach bed controls independently (if applicable), using splints or other devices to help hold the body in the correct position, and other actions required to keep the person with tetraplegia's body in a position that prevents complications (including pain, skin damage, range of motion problems, falls) and maximizes their ability to function.
11. Proper Body Positioning in Wheelchair. Includes both static sitting and weight-shifting techniques. May include supporting shoulders to avoid dislocation, preserving tightness in hands when needed for grasping objects (tenodesis), positioning body to avoid excessive pressure, ensuring ability to reach wheelchair controls independently (if applicable), using splints or other devices to help hold the body in the correct position, and other actions required to keep the person with tetraplegia's body in a position that prevents complications (including pain, skin damage, range of motion problems, falls) and maximizes their ability to function.
12. Performing Range of Motion. Includes performance of exercises to prevent loss of motion in arms, legs, hands, or other body parts. Technique of moving and monitoring for signs of problems (such as grimacing, increase spasticity, etc.) may be considered in scoring.

Domain 2. Mobility in Daily Life

13. Transfers Between Level Surfaces.^{*} Includes all aspects of directing/performing transfers *between surfaces that are level*. Typically includes transfers between bed, wheelchair, and commode/shower chair, as long as both transfer surfaces are level with one another. Includes appropriate use of

equipment, appropriate set-up of the surfaces involved in the transfer, receiving/providing assistance as needed to perform the transfer and avoid a fall, etc.

14. Transfers Between Uneven Surfaces.^{*} Includes all aspects of directing/performing transfers *between surfaces that are uneven (not level with one another)*. Includes car transfers but excludes floor to chair transfers, which are covered under Emergency Transfers below). May include transfers between other surfaces (bed, wheelchair, commode/shower chair) if the transfer surfaces are not level with one another.

* When determining whether to score a particular transfer as part of Transfers Between Level Surfaces or Transfers Between Uneven Surfaces, remember that the key element is the “level-ness” of the transfer, not the types of surfaces involved (bed, wheelchair, shower chair, etc.). When in doubt, include a transfer you consider to be more difficult under Uneven Surfaces rather than Level Surfaces.

15. Emergency Transfers. Pertains to transfers that may be needed in case of emergency, such as getting up from the floor or getting out of the chair quickly in case of malfunction or emergency requiring evacuation outside of the chair.
16. Moving Around in Bed. Includes receiving/providing appropriate assistance to move from sitting to supine (laying), rolling, scooting, etc.
17. Mobility (Walking or Wheelchair) on Flat Surfaces. Includes receiving/providing appropriate assistance to move (via wheelchair or walking) over level surfaces. Typically includes interior floors but may also include paved outdoor surfaces if they are smooth. Includes guarding techniques, cueing or assistance for maneuvers in tight spaces, use of manual mode for power chair users.
18. Mobility (Walking or Wheelchair) on Uneven Surfaces. Includes receiving/providing appropriate assistance to move (via wheelchair or walking) over uneven surfaces, such as grass, ramps, wheelchair lifts, curbs, stairs (as applicable to the person receiving assistance). Includes guarding techniques, cueing or assistance to maneuver in tight spaces, use of manual mode for power chair users.
19. Managing Wheelchair Parts. Includes manipulating parts of the wheelchair to allow for transfers, wheeling or driving the chair, storage or transport of the chair. Includes moving and positioning armrests, footrests, headrest, drive control, or other parts. For manual wheelchair users, includes removing and replacing wheels and folding the chair (if applicable). For power wheelchair users, includes charging the chair but excludes driving it into a vehicle (which would be considered part of Walking or Wheeling on Uneven Surfaces above).

Domain 3. Other Daily Activities

20. Eating and Drinking. Includes directing a caregiver and/or providing assistance in bringing food and drink to the mouth. Excludes cooking and food selection. Includes positioning the person with tetraplegia appropriately (to prevent food going into the airway, enable him/her to hold/reach utensils, cups, etc.), providing food in appropriate bite sizes and at an appropriate rate, etc.

21. Bathing. Includes directing a caregiver or providing assistance in washing body and hair via shower, bed bath, or other means. Excludes transfers involved in bathing, which are covered under either Transfers Between Level Surfaces or Transfers Between Uneven Surfaces depending on the setup.
22. Grooming. Includes washing face and hands, brushing and flossing of teeth, shaving, styling hair and (if applicable) applying makeup in the manner preferred by the person receiving assistance.
23. Dressing. Includes dressing of the upper and lower body in a manner that avoids complications (as might occur from clothing or shoes that are too tight) and achieves the appearance desired by the person receiving assistance.

Part B

Domain 4. Communicating Effectively

24. Using Appropriate Language. Includes addressing the other member of the care team (care director or caregiver) using their preferred title or name, expressing gratitude, avoiding negative words or insults.
25. Using Appropriate Tone of Voice. Includes speaking at a volume and pace that is conducive to understanding, using a tone that is appropriate to the situation. Also includes non-verbal aspects of communication, such as eye contact, smiling (when appropriate), avoiding negative gestures or actions (sighs, groans, eye-rolling, etc.)
26. Detecting/Responding to Misunderstanding or Uncertainty. Includes ability to recognize when the other member of care team is uncertain about what to do or may have misunderstood what has been said and then taking appropriate actions to clarify what is needed. Signs of misunderstanding may include hesitance in speaking or performing a task, or actions or gestures (such as furrowed brow, sighs, groans, frown, unusual silence, etc.). Indicators that the care director or caregiver is appropriately detecting and responding to uncertainty include confirming an instruction or request, adding clarification, asking if additional or different instructions would be helpful, etc.
27. Rephrasing or Changing Instructions When Needed. Includes ability to use different words or other techniques (such as demonstration--when feasible, reference to a document, picture, or video, etc.) to help the other member of the care team understand what is being said or requested.
28. Speaking up for Needs or Concerns. Includes the extent to which members of the team speak up when they have a question or concern, rather than allowing someone else to speak for them or not speaking until after a problem occurs.
29. Providing Helpful Feedback. Includes telling the other member of the care team what worked well and what did not in the care interaction, using language that is respectful and non-accusatory in tone.
30. Being an Active Listener. Includes behaviors such as making eye contact, allowing the speaker to speak without interruptions (except when needed to clarify what is being said), restating what was said to make sure it was understood, etc.

Part C**Domain 5. Home and Community Living**

31. Child Care. Includes directing/providing assistance with addressing the child's basic needs (bathing, food, clothing, diapering, toileting) as well as participating in activities together (games, homework, etc.)
32. Pet Care. Includes directing/providing assistance with addressing the pet's basic needs (feeding, taking care of waste, cleaning/grooming, other aspects of maintaining the health and well-being of a pet), as well as participating in activities together.
33. Maintaining a Clean and Healthy Home Environment. Includes assistance related to house cleaning as well as laundry.
34. Food Preparation. Includes assistance with shopping, meal planning, cooking, storage/packaging of food, etc.
35. Phone and Computer Access. Includes directing/providing assistance with use of a telephone (land-line or cellular), tablet, laptop computer, desktop computer, or other electronic device used for communication, information access, control of environment, or other purposes. *Note: This task may overlap with others that involve phone or computer use, such as Work, School, or Leisure Activities. Behaviors that relate both to phone/computer use and to the performance of another task may be considered in the scoring of both tasks.*
36. Managing Legal/Financial Documents and Affairs. Includes directing/providing assistance with handling of mail, bills, banking, and other affairs.
37. Maintaining Stock of Supplies. Includes directing/providing assistance with inventory of medical and household supplies, ordering, and organization of supplies once received.
38. Maintaining Equipment. Includes directing/providing assistance with inspecting equipment (wheelchairs, cushions, shower chair, commode, mattress, etc.) for signs of wear and tear or malfunction, cleaning equipment (to maintain its appearance and/or function), making arrangements for routine checks or repairs by technicians when appropriate.
39. Transportation and Travel Planning. Includes directing/providing assistance with packing appropriate supplies, verifying accessibility of transportation and lodging, managing time to ensure on-time arrival, etc.
40. Work, School, or Leisure Activities. Includes directing/providing assistance with activities specifically related to taking classes, performing job functions, participating in recreational activities, etc.
41. Performing Exercises for Strength or Fitness. Includes proper performance of recommended home exercises such as functional electrical stimulation cycling, strengthening exercises, etc.

- 42. Facilitating Intimate Relationships. Includes working with a caregiver to prepare for sexual activities, including appropriate positioning, adjustment of catheters or other equipment, contraceptive use, etc.
- 43. Accessing Resources When Needed. Includes recognizing when outside assistance may be needed (from equipment supplier, clinician, other members of support system), working with caregivers to identify an appropriate source of assistance and the best way of contacting that source, and effectively communicating with that resource to obtain the needed assistance.

Domain 6. Managing Personnel

Note: Tasks in this section apply only to those who be using the services of hired caregivers. Only the care director's performance is scored in this section.

- 44. Recruiting and Interviewing. Includes advertising for help, scheduling interviews, conducting interviews.
- 45. Establishing Expectations and Policies. Includes describing care needs, setting rules of conduct, etc.
- 46. Coordinating Coverage and Schedules. Includes setting schedule for caregivers and communicating that to others as needed; identifying backup plan in case of staff illness or other issue.
- 47. Transitioning to New Staff as Needed. Includes communicating intent to terminate work relationship, preparation of documents, etc.

7. Scoring Criteria

Scores are given for care directors, caregivers, and the care team for three different scales: Safety, Problem-Solving (Parts A and C only), and Communication (Part B only). These scales reflect different aspects of direction of care or caregiving performance. The scores for each scale reflect the extent to which the care director, caregiver, or team are able to appropriately execute that aspect of task performance without assistance from the trainer. Assistance may include physical help, cueing or reminders given via words or gestures, responding to questions asked by the care director or caregiver, or other forms of help. Descriptions of each scale and their scoring criteria are given below:

Safety Scale: Addresses ability to direct or perform a care task in a manner that prevents illness or injury (physical, emotional, or financial) to the person receiving assistance or his/her caregiver.

Safety Scoring: How much of the care direction/caregiving is performed safely *without assistance* from the trainer?

1. None – Requires assistance from the trainer to direct or perform all of this task safely
2. Some – Able to direct or perform *some* of this task safely without assistance from trainer
3. Most – Able to direct or perform *most* of this task safely without assistance from trainer
4. All – Able to direct or perform *all* of this task safely without assistance from the trainer

Problem-Solving Scale: Relates to the ability to adjust how a task is directed or performed in response to unusual or challenging circumstances to maintain safety and/or increase efficiency.

Problem-Solving Scoring: How much of the problem-solving process can be done *without assistance* from the trainer?

1. None – Requires complete assistance from trainer to identify problems and implement solutions
2. Some – Able to identify problems, requires assistance from trainer to identify and implement solutions
3. Most – Able to identify both problems and appropriate solutions but requires assistance from trainer to implement solutions
4. All – Able to identify problems and appropriate solutions, and can implement solutions without assistance from trainer

Communication Scale: Relates to the ability of the care director and caregiver to communicate effectively and appropriately with one another.

Communication Scoring: How much of the time is communication occurring effectively *without assistance* from the trainer?

1. None – Unable to communicate effectively without assistance from trainer
2. Some – Able to communicate effectively *some* of the time without assistance from trainer
3. Most – Able to communicate effectively *most* of the time without assistance from trainer
4. All – Able to communicate effectively *all* of the time without assistance from trainer

Note that “None” and “All” should be interpreted as “nearly none” and “nearly all.” A score of “None” may still be given if a task is done without help but only on rare occasions. Similarly, a score of “All” may

still be given if occasional errors are made but are self-corrected (therefore not requiring assistance) or if assistance is needed on rare occasions or when there are very unusual circumstances.

There is not a strict percentage associated with “some” or “most”—we leave it to the judgment of the trainer to determine which score best characterizes the ability of the care director, caregiver and or team being scored.

8. General Principles for Completing the TEAM Tool

Scores are based on observations of care director and caregiver behavior made by the trainer(s) during training. The TEAM Tool is designed to be completed by rehabilitation professionals (or other “trainers” as defined above) based on observations that they make during the process of training people with tetraplegia to direct their care and training family members or others to perform care tasks (such as assisting with a transfer or catheterization). Scores should be based on behaviors observed during practice of direction of care or caregiving whenever possible, to the extent that practice of these tasks occurs in typical clinical care.

For those tasks that are not feasible to practice in clinical care (such as responding to autonomic dysreflexia) an assessment may be made via a discussion of how the person with tetraplegia would direct the task or how his/her caregiver would perform the task. (It is anticipated that most of the tasks in Part C, which involves community skills and personnel management, will need to be assessed in this manner.)

It is not necessary for the person with tetraplegia AND his/her caregiver to be present for an assessment to take place—in the event that a caregiver is not present or available, a rehabilitation staff member may serve as the caregiver, with direction of care provided by the person with tetraplegia.

Scores are only given for tasks that *involve the assistance of a caregiver*. The TEAM Tool is designed to provide information about direction of care and caregiving ability. Any task that the person with tetraplegia is able to do on his/her own (or is being trained to do on his/her own) should not be scored.

For example, a person with tetraplegia may be trained to drive a power wheelchair over flat surfaces. If the goal of training is for the person with tetraplegia to be able to perform this task without any assistance (supervision, cueing or physical assistance) from a caregiver, then this task should be marked “Not applicable” and should not be scored in the TEAM Tool.

If however, the expectation is that the person with tetraplegia will utilize supervision, cueing, or other assistance from a caregiver for power wheelchair driving over level surfaces post-discharge, this task should be scored.

No changes in typical clinical care are required for the TEAM Tool to be completed. The TEAM Tool is intended to assist the process of training people with tetraplegia and their caregiver by encouraging evaluation of these skills by the rehabilitation team, and providing a mechanism for documenting and communicating assessment findings. The TEAM Tool may “inspire” changes to the training process by drawing attention to areas in which training is needed, but changes in typical care are NOT required for the team tool to be completed.

Decisions about what skills to train, how to train them and when to provide training should be driven by clinical considerations and not by the need to complete the tool. Clinicians may choose to incorporate

the tool in their training efforts in whatever ways feel most appropriate, including reviewing it with patients/caregivers during training, discussing with other members of the patient's clinical team, etc.

Any trainer may score performance in any task that he/she observes. While the scope of practice differs among clinical disciplines (occupational therapy, physical therapy, nursing, etc.), there is often overlap between disciplines in the topics of training. For example, both nurses and occupational therapists may provide education related to intermittent catheterization. For purposes of pilot-testing, any trainer may score any task that is considered part of his/her training activities, regardless of his/her clinical discipline.

Scores are based on observations made during a one week look back period. Scores given on the TEAM Tool are based on observations of behavior made in the week prior to (and including) the date the trainer is completing the tool. A look back period of this length is provided to maximize opportunities to observe various skills, since it is rarely feasible to observe all skills in a single day or even over 2-3 days. It also gives trainers flexibility to complete the tool when their schedules permit.

Scores should be given based on the trainer's assessment of the CURRENT abilities of the care director or caregiver. For tasks that are performed multiple times during the look back period, performance may vary over the course of the week. The trainer should pick the score that he/she feels best reflects the abilities of the care director or caregiver as of the date the TEAM Tool is being completed.

For example, in a situation where performance improved over the course of the week, and less help was needed from the trainer, the score given on the TEAM Tool should be based on the more recent observations.

In other situations, performance may be inconsistent, such that lot of help from the trainer is needed on some days and little on others, with no discernable trend of improvement. In such a case, it may be more appropriate to give a score that reflects the poorer performance, even if little help was needed at the most recent observation. If inconsistency of performance is related to task setup (an "idealized" setup vs. one closer to that of the home environment) scoring should be based on the setup that is closest to that of the home environment.

Trainers should assign scores based on the perceived need for assistance, even if assistance was not actually provided. There may be circumstances in which assistance may be needed but is not actually given. For example, a care director and caregiver may be communicating inappropriately early in the training process but the trainer has not yet developed the rapport necessary to intervene productively. In such situations, the trainer should assign a score based on the assistance he/she would have provided if circumstances permitted.

The TEAM Tool is designed to be completed at multiple points in time. The TEAM Tool is designed to be used at multiple time-points so that changes in skill level can be documented over time. The tool may be completed as often as deemed appropriate by the trainer(s). For purposes of pilot testing, the target windows for completion of the tool are:

- Within two weeks of admission to inpatient rehabilitation
- Near the midpoint of the inpatient rehabilitation stay (the middle two weeks of the stay, based on the best available information about anticipated discharge date)
- Within two weeks prior to discharge

If completion of the tool within these windows is not feasible, the research team will consult with trainers to identify appropriate timeframes.

9. Step-By-Step Instructions for Pilot-Testing of the TEAM Tool

1. **Select a day** within the target window to complete the TEAM Tool and obtain a TEAM Tool form. (Research staff will notify you of the window dates and will provide copies of the forms.)
2. **Fill out the date and ID fields** on the first page (research staff can fill in the remaining pages for you, unless you prefer to label them yourself).
 - ☐ Enter your clinician ID. IDs will be provided by the research staff.
 - ☐ Write the assessment date, which is the date on which you are completing the assessment form. All scores should be entered on the same day, based on observations made during care director and caregiver training during the week prior to (and including) the date on which you are completing the form. This period is referred to as the **look back period**.
 - ☐ Write the ID of the person with tetraplegia who is being trained. IDs will be provided by the research staff.
 - ☐ If a caregiver was trained during the look back period, enter the ID for that caregiver (also provided by research staff). Only one pairing of care director and caregiver should be assessed on a single TEAM Tool form. If more than one caregiver was trained during the look back period, enter the ID for the person who is most likely to be the primary caregiver and base your scores on the performance of this care director-caregiver team. (You may complete additional TEAM Tool forms for other caregivers if you wish, but this is optional.) If no caregiver was trained during this week, and you served the role of the caregiver during direction of care training, leave the caregiver ID blank.
3. **Complete scores for the tasks presented in Parts A and B.** For each task:
 - ☐ Determine if the task applies to the person with tetraplegia. Mark the task “NA” (not applicable) if:
 - It is not medically or functionally relevant to the person with tetraplegia (such as “Managing Wheelchair Parts” for someone who not a wheelchair user)
 - It does not require the assistance of a caregiver [such as “Mobility (Walking or Wheelchair) on Flat Surfaces” in the case of a person with tetraplegia who is being trained to be independent in power wheelchair mobility]
 - ☐ If the task is applicable, assign scale scores (Safety and Problem-Solving for Part A, Communication for Part B) as follows:
 - Use the scoring criteria on the bottom of page 2 of the TEAM Tool (and also described in this manual on page 13 to guide your scores.
 - Enter scores in the columns relevant to those who received training in the task during the look back period:
 - Blue column only: Only the care director (person with tetraplegia) received training
 - Blue and yellow columns: Care director and caregiver received training, but did not practice performing a task together

- **Blue, yellow, and green columns:** If both a care director and caregiver were trained and they practiced one or more tasks in that area together
 - A formal assessment is not necessary to enter a score of 1 (None) in any column—if the person (or team) being assessed has not received training or has not yet been asked to demonstrate any tasks within that area, enter a score of 1, indicating that they are not yet able to do any tasks in the task without assistance.
 - Leave a task blank only if it falls outside the scope of your practice (meaning that you do not provide any training relevant to this area and do not have expertise required to evaluate the performance.) If you wish, you may enter a dash in the box rather than leaving it blank.
 - Note that while inter-personal issues are often addressed by a psychologist, the tasks in the domain of Communicating Effectively are considered to be within the scope of all disciplines.
 - ❑ If there is another task in a domain that is relevant to the person with tetraplegia but is not addressed in other tasks (such as wound care), write this task on the line marked “_____ (Other)” and assign scores as discussed above.
4. **(Optional) Complete scores for the tasks presented in Part C.** The tasks in Part C are considered more advanced or otherwise may fall outside the scope of what is typically covered in inpatient rehabilitation, therefore this section is optional. It is included in recognition of the importance of these skills for long-term success in the community and to prepare for later piloting of the tool in settings beyond inpatient rehabilitation. If you choose to complete Part C, please follow the instructions listed in item 3 above for Parts A and B.
5. **Calculate Domain Scores.** *(If pressed for time, you may leave this to research staff to complete for you.)* Domain scores are calculated for each of the six domains: (Preventing Complications, Mobility in Daily Life, Personal Health and Appearance, Communicating Effectively, Home and Community Skills, Personnel Management Skills). Within each of these six domains, calculate domain scores for each column as follows:

$$\text{Domain score} = X \div Y$$

Where: X = Sum of the scores given to the tasks within the domain
(Enter this in the first blank of the “__ ÷ __” in the column)

Y = Number of tasks scored (not marked N/A or left blank) in the domain
(Enter this in the second blank in the “__ ÷ __” in the column)

If no scores appear in a particular column, leave the Domain Score lines blank.

6. **Calculate Overall Scores for Parts A, B, and C.** (You may leave this to research staff to complete for you.) Within each Part, calculate overall scores for each column as follows:

$$\text{Overall score} = P \div Q$$

Where: P = Sum of the scores given to the tasks within the Part
(Do not include the Domain Scores you calculated, only the scores for the tasks themselves. Enter in the first blank of the “__ ÷ __” in the Overall Score row.)

Q = Number of tasks scored in that Part
(Enter in the second blank in the “__ ÷ __”)

If no scores appear in a particular Part, leave the Overall Score lines blank.

7. **Note feedback on your experiences using the tool.** Space is provided on page 4 of the TEAM Tool packet for you to share comments about difficulties with scoring, tasks that were not included, uncertainties in the instructions, etc. The purpose of pilot-testing is to identify what works well and what does not, so all feedback is welcome.
8. **Return form to designated location for collection by the research team.** A member of the research team will collect the forms on a regular basis.

9. Resources on Care Direction and Caregiving
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<u>Title/Description</u>	<u>Accessible/Downloadable From</u>
A Step-by-Step Guide to Training and Managing Personal Assistants: Consumer Guide)	http://familyserviceswe.ca/sites/default/files/documents/a%20step-by-step%20guide%20to%20training.pdf
How to Successfully Hire and Manage a Personal Care Assistant: For People with Spinal Cord Injury (also available as iBook)	http://www.sfphysio.fr//docs/2015131740_how-to-successfully-hire-and-manage-a-personal-care-assistant-for-people-with-spinal-cord-injury.pdf
Managing Personal Assistants: A Consumer Guide (PVA)	http://www.pva.org/atf/cf/%7BCA2A0FFB-6859-4BC1-BC96-6B57F57F0391%7D/persasstfc6d.pdf
Personal Care Assistance: How Much Help Should I Hire	https://craighospital.org/resources/personal-care-assistance-how-much-help-should-i-hire
Personal Care Assistants: How to Find, Hire, & Keep	https://craighospital.org/resources/personal-care-assistants-how-to-find-hire-keep
Long Term Caregivers: For Better and For Worse	https://craighospital.org/resources/long-term-caregivers-for-better-and-for-worse
As the Years Go By: Accepting New Help	https://craighospital.org/resources/as-the-years-go-by-accepting-new-help
Video: Perspectives From Those Providing Care	http://sci.washington.edu/care_providers/index.asp
Video: Managing Personal Caregivers: A Panel Discussion	http://sci.washington.edu/caregivers/index.asp
Video: Personal Caregivers: Tips, Tricks and Tales from Individuals with Spinal Cord Injury	http://sci.washington.edu/info/forums/reports/caregivers.asp
SCI Forum Report – Personal Care Attendants	http://sci.washington.edu/info/forums/reports/attendant.s.asp
The Rough Guide to Managing Personal Assistants	http://www.independentliving.org/docs6/vasey2000.html
Caring for Caregivers – SCI InfoSheet	http://www.spinalcord.org/resource-center/askus/index.php?pg=kb.page&id=299
Long Term Caregivers: For Better and For Worse	https://craighospital.org/resources/long-term-caregivers-for-better-and-for-worse
Hiring In-Home Help – Family Caregiver Alliance	https://www.caregiver.org/hiring-home-help

Appendix 11

Team Tool Clinician Debriefings – Summary of Feedback

Suggested changes are marked with **.

[bracketed text] indicates clarification added by Jeanne Zanca (not provided by clinicians)

Comments	Suggestions for Changes or Future Use
General	
<ul style="list-style-type: none"> - Gave a good sense of what they [care director/caregiver] should be able to do when they get home - Hard to find time to complete the tool because there is so much else going on with these patients [the clinical cases where direction of care/caregiver training is most relevant are also the most complex] - Had to remember to do it - Admission assessments were fast - A lot of the time was in flipping back and forth between tool and manual 	<ul style="list-style-type: none"> - Make the form electronic in some way (spreadsheet, part of electronic medical record, other) - Include a popup that reminds you what is included in each task so you don't have to look things up in the manual - If electronic form, could be more flexible in scoring what is relevant - Overall suggestions for reducing time burden: <ul style="list-style-type: none"> o Score problem-solving overall o Divide by discipline o Electronic version o Consolidate tasks when possible
Tasks	
<ul style="list-style-type: none"> - Very exhaustive list of topics to cover (good thing as a reminder, but also a little intimidating) - List was great – everything in one spot, raised things to cover - Serves as a checklist, self-check - Hard to remember what goes into each task, had to look this up which took time 	<u>Part A</u> <ul style="list-style-type: none"> - Blend Positioning in bed and Positioning in wheelchair (see if generally scored the same to guide decision?) - Don't separate out "preventing infection" [incorporated under other tasks] - Blend Caring for skin and Detecting signs of damage (detecting damage is like a problem-solving component of the care) - Transfers can be combined somehow, particularly since most of these patients are using Hoyers (especially at first). Maybe give option of saying "mechanical lift to all surfaces."

	<ul style="list-style-type: none"> - Combine wheelchair mobility on flat and uneven surfaces (maybe change to flat vs. community for surfaces or hospital vs. community) - Add weight shifts somewhere—doesn't seem to have the prominence it should [clarified that it was part of repositioning but that may need to be more specific]. Same for assisted cough, vent care. - Add being able to call for help in an emergency to Part A - Consider relocating some Part C tasks to Part A: <ul style="list-style-type: none"> o Maintaining equipment o Supplies o Accessing resources <p><u>Part B</u> (Communication)</p> <ul style="list-style-type: none"> - Speaking up and Providing helpful feedback seem to overlap because both are about being proactive in your communication (but someone else said keep Speaking up as is) - Rephrasing and Responding to uncertainty [rephrasing would be one way you respond] BUT others said that the rephrasing was really important. - Combine Tone and Appropriate Language (rarely see issues with one but not the other) - One participant said “Active listener” is barometer for healthy relationship – keep that - Consider looking at what was scored the same in the communications section to see which things could be blended
Scoring (In General)	
<ul style="list-style-type: none"> - Generally liked that there wasn't a percentage specification for the different scores - Generally liked 4 levels and not having an exact middle. - Liked that scoring didn't have a neutral or midpoint (otherwise would have picked that a lot) 	<ul style="list-style-type: none"> - Clarify none vs. some (Feels like some people know a tiny bit, so not none, but not enough to be “some”. Hard to know what “Some” meant.) - Note that some participants felt we do need “none” for people who really do know nothing

<ul style="list-style-type: none"> - Scores coincided with clinical concerns about patient's preparedness for discharge - Not always sure what "some" meant - There were times a patient would be scored 1 even though he/she learned something because there was so much in the task [and he/she was not more than 1 on all pieces] - Liked the large assessment window - Liked separation between safety and problem-solving (can be safe but not be able to problem-solve); however this also increased the scoring workload. - Felt consistent within themselves, but not sure how others would score - Keep in mind that environment drives the score <ul style="list-style-type: none"> o Ratings on this tool [scored in the hospital] will be higher than in their own environment o May not have challenged the family completely in the hospital environment o Hard to conjecture how they will do when they get home o Hard to remove yourself from the situation [to score based on what they are likely to do at home] o Failure outside the setting may be happening for other reasons [like emotional adjustment, accessibility, etc.] - Scores could be higher if given by a therapist who is not as aware of SCI rehab (and all the things the patient and caregivers need to do) - Found myself flipping between task descriptions and the scoring criteria to figure out how to score. If only some of the task was relevant to someone, hard to decide on score. - Outpatient therapist might rate differently [standard might be different] 	<ul style="list-style-type: none"> - Consider there being a threshold to score problem-solving (if not safe, can't problem-solve) - Consider scoring 0-3 instead of 1-4 - Consider not being able to score problem-solving until you get to a certain threshold of safety (generally felt these were different concepts, though, and shouldn't be in one continuum) - Having to score problem-solving for every tasks adds burden. <ul style="list-style-type: none"> o Consider overall problem-solving score (if good in one area, generally good in others, if good at problem-solving generally safe) o Maybe Problem-solving belongs in communication? o Maybe separate problem-solving for team [only] (problem-solving was most valuable for team) o When team worked [was generally because of problem-solving] - If drop problem solving so that you are rating only one thing for each task, what should that be? <ul style="list-style-type: none"> o Consider rating competence rather than safety (includes safety and problem-solving) o Other things to consider rating are whether they accomplished the task, time effectiveness (efficiency of effort)
--	---

<ul style="list-style-type: none"> - Therapist (OT) didn't feel she could score bowel and bladder or that it would be incomplete because they did not do the full set of steps – didn't observe directly - Had a gut sense of what felt "safe"; didn't feel a need for a definition of safe 	<ul style="list-style-type: none"> – Split scoring up by discipline; assign tasks to those most knowledgeable of full details of performance
Scoring Caregivers and Team	
<ul style="list-style-type: none"> - Felt team column should definitely stay - Did a good job of capturing dynamics of when things did and didn't work between the care director and caregiver - When there is an absence of caregiver, frustrating because a lot of the form is left blank - Caregivers changed so frequently that scores did not grow [have a chance to improve over time] - Less opportunity to see caregiver without me helping [If I am helping it is hard to truly assess what they can do for themselves] - Team score gives added value - Team score most useful when observing what patient/caregivers do in preparation for discharge - Hard to score team when limited time to observe (when you are actively teaching, such as when all the training had to happen in a few days at the end) - Challenging when there are multiple caregivers (not all have same level of competence) - When the team scored low, generally because of communication - Interacting with clinician [to practice care direction] is different than with family (more problems with family) 	<ul style="list-style-type: none"> - How to handle it when one partner is doing too much or too little? Not sure what to do in situations where the patient is driving what is happening and the caregiver is just following their instructions (and has no knowledge or skill of his/her own), as is often the case if someone comes in for last-minute training. Doesn't seem right to score that the caregiver is safe or able to problem-solve, even if they didn't do anything wrong. Need guidance about this situation and how to score. Maybe indicate percent of who is contributing what? - Consider giving option of noting barriers to family training for scores of 2 and below (overall section at end, not for each task) <ul style="list-style-type: none"> o Poor attendance o Caregivers changing throughout stay o Motivation o Cognition o Language/cultural barrier o Complexity of injury o Physical status
Use	
<u>Mechanics</u> <ul style="list-style-type: none"> - How to talk with each other about what you filled in: 	<ul style="list-style-type: none"> - Consider shifting admission assessment to later, then redo at week x, week y (instead of admission, midpoint, etc)

<ul style="list-style-type: none"> - Don't do in team conference (no time) - Could help inform goal-writing and then the goals get discussed in team conference - Showing patient and family their score in a qualitative way (not a set of numbers) could be good feedback, especially at midpoint. Showing it at discharge could be discouraging. <p><u>Benefits</u></p> <ul style="list-style-type: none"> - Tool scores could be useful in determining who might be appropriate to be referred to transitional support program; continue to score post-discharge and see if scores improve - If score 2 or below at midpoint, could be a trigger to case management to schedule more extensive training for caregivers - Could help demonstrate value of length of stay/programming - Could help identify factors contributing to complications - Could be useful in communicating with PCA, doctor 	<ul style="list-style-type: none"> - Some said good to let whole team contribute to scoring so you evaluate performance under different circumstances; others said lots of items made it lengthy and time-consuming, suggest splitting among disciplines. - Consider asking patients/family if they are feeling ready; could use in family meeting
Other	
<ul style="list-style-type: none"> - Would be really interesting to see what a day program therapist would score (likely to score much lower than the inpatient therapist because of the environment, context) - Made me more mindful of what director/caregiver will have to face - Placed emphasis on the communication piece, encouraged more practice of the communication aspects - Would be interesting to see how the team (care director and caregiver) perceived they were doing 	

Appendix 12

Teaching Effective Assistance Management (“TEAM”) Tool Form

(Post-Piloting Revised Version – Marked Changes and Clean Versions)

= OVERALL SCORE for Part A		<input type="checkbox"/> <u>Care Director</u>	& <u>Caregiver</u>	= <u>Team</u> <input type="checkbox"/>
TASKS – Part B		N/A	Communication	Communication
<u>Communicating Effectively</u> (Domain 4)				
Using Appropriate Words and Tone of Voice		<input type="checkbox"/>		
Acknowledging Concerns		<input type="checkbox"/>		
Rephrasing or Changing Instructions When Needed		<input type="checkbox"/>		
Providing Helpful Feedback		<input type="checkbox"/>		
Being an Active Listener		<input type="checkbox"/>		
_____ (Other)				
Sum of scores for this domain ÷ # of tasks scored		____ ÷ ____	____ ÷ ____	____ ÷ ____
= COMMUNICATION SCORE (OVERALL SCORE Part B)				

Scale Definitions and Scoring Criteria for Parts A and C:

For each scale, select the score that best reflects the abilities of the person (care director or caregiver) or team (care director and caregiver working together), considering all behaviors observed over the past week. If performance varied during this period, select the score that best represents the **CURRENT** abilities of the care director, caregiver, or team. Mark "N/A" if a task does not require assistance from a caregiver or is not medically or functionally relevant to the person with tetraplegia.

Safety Scale: Addresses ability to direct or perform a care task in a manner that prevents illness or injury (physical, emotional, or financial) to the person receiving assistance or his/her caregiver.

Safety Scoring: How much of the care direction/caregiving is performed safely *without assistance* from the trainer?

1. None – Requires assistance from the trainer to direct or perform all of this task safely
2. Some – Able to direct or perform some of this task safely without assistance from trainer
3. Most – Able to direct or perform most of this task safely without assistance from trainer
4. All – Able to direct or perform all of this task safely without assistance from the trainer

Problem-Solving Scale: Relates to the ability to adjust how a task is directed or performed in response to unusual or challenging circumstances to maintain safety and/or increase efficiency.

Problem-Solving Scoring: How much of the problem-solving process can be done *without assistance* from the trainer?

1. None – Requires complete assistance from trainer to identify problems and implement solutions
2. Some – Able to identify problems, requires assistance from trainer to identify and implement solutions
3. Most – Able to identify both problems and appropriate solutions but requires assistance from trainer to implement solutions
4. All – Able to identify problems and appropriate solutions, and can implement solutions without assistance from trainer

Scoring Criteria for Part B:

Communication Scale: Relates to the ability of the care director and caregiver to communicate effectively and appropriately with one another.

Communication Scoring: How much of the time is communication occurring in an appropriate manner *without assistance* from the trainer?

1. None – Unable to communicate effectively without assistance from trainer
2. Some – Able to communicate effectively *some* of the time without assistance from trainer
3. Most – Able to communicate effectively *most* of the time without assistance from trainer
4. All – Able to communicate effectively *all* of the time without assistance from trainer

TASKS – Part C (OPTIONAL for Pilot-Testing)		<u>Care Director</u>		<u>& Caregiver</u>		<u>= Team</u>	
		Safety	Problem-Solving	Safety	Problem-Solving	Safety	Problem-Solving
Home and Community Living (Domain 5)							
	Child Care (if applicable) <input type="checkbox"/>						
	Pet Care (if applicable) <input type="checkbox"/>						
	Maintaining a Clean and Healthy Home Environment <input type="checkbox"/>						
	Food Preparation <input type="checkbox"/>						
	Managing Legal/Financial Documents & Affairs <input type="checkbox"/>						
	Transportation and Travel Planning <input type="checkbox"/>						
	Work, School, or Leisure Activities <input type="checkbox"/>						
	Performing Exercises for Strength or Fitness <input type="checkbox"/>						
	Facilitating Intimate Relationships <input type="checkbox"/>						
	_____(Other)						
	Sum of scores for this domain ÷ # of tasks scored	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____
	= HOME/COMMUNITY SCORE						
Managing Personnel (Domain 6)							
	Recruiting and Interviewing <input type="checkbox"/>			<p>Do Not Score “Managing Personnel” Items in These Columns</p> <p>These items will be scored only for the Care Director.</p> <p>Use the HOME/COMMUNITY SCORE for Domain 5 as the OVERALL SCORE for Part C for the Caregiver and the Team.</p>			
	Establishing Expectations and Policies <input type="checkbox"/>						
	Coordinating Coverage and Schedules <input type="checkbox"/>						
	Transitioning to New Staff as Needed <input type="checkbox"/>						
	_____(Other)						
	Sum of scores for this domain ÷ # of tasks scored	____ ÷ ____	____ ÷ ____				
	= MANAGEMENT SCORE						
	Sum of task scores in domains 5-6 ÷ # tasks scored	____ ÷ ____	____ ÷ ____				
	= OVERALL SCORE for Part C						

Share your feedback!

Please use the space below (or email – see below) to note general comments or any difficulties you encountered in using the TEAM Tool. **When in doubt, fill out the form based on what feels most right to you and comment below about what you were uncertain about.** These could include difficulties deciding on a score, tasks that are not listed, areas where more guidance or clarity is needed in the instructions, etc. ANY ideas you may have for improving the content, format, or use of the TEAM Tool itself or the Instruction Manual are welcome.

For questions about the TEAM Tool or the study in general, please contact:

Jeanne Zanca, PhD, MPT

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Phone: 973-324-3558 Email: jzanca@kesslerfoundation.org

Thank you for your help!

Please return this form to the designated location for collection by the study team.

Clinician Initials: _____ Discipline: _____

Date Completed: _____

TASKS – Part A

Preventing Complications (Domain 1)

Using Ventilator Properly ☐

Keeping Airways Clear ☐

Managing Blood Pressure ☐

Responding to Autonomic Dysreflexia ☐

Maintaining Healthy Skin ☐

Emptying Bowels Regularly ☐

Emptying Bladder Regularly ☐

Using Medications as Prescribed ☐

Proper Body Positioning ☐

Shifting Weight Regularly ☐

Performing Range of Motion ☐

_____ (Other)

Sum of scores for this domain ÷ # of tasks scored

= PREVENTING COMPLICATIONS SCORE

Mobility in Daily Life (Domain 2)

Transfers Between Surfaces ☐

Emergency Transfers ☐

Moving Around in Bed ☐

Moving Around by Wheelchair ☐

Managing Wheelchair Parts ☐

_____ (Other)

Sum of scores for this domain ÷ # of tasks scored

= MOBILITY SCORE

Other Activities (Domain 3)

Eating and Drinking ☐

Bathing ☐

Grooming ☐

Dressing ☐

Phone and Computer Access ☐

Maintaining Stock of Supplies ☐

Maintaining Equipment ☐

_____ (Other)

Sum of scores for this domain ÷ # of tasks scored

= OTHER DAILY ACTIVITIES SCORE

Sum of task scores in domains 1-3 ÷ # tasks scored

Care Director

Initials: _____

Safety

Problem-Solving

& Caregiver

Initials (or relationship): _____

Safety

Problem-Solving

= Team

Safety

Problem-Solving

N/A

= OVERALL SCORE for Part A		<input type="checkbox"/> <u>Care Director</u>	<input type="checkbox"/> <u>& Caregiver</u>	<input type="checkbox"/> <u>= Team</u>
TASKS – Part B		N/A		
Communicating Effectively (Domain 4)		Communication	Communication	Communication
Using Appropriate Words and Tone of Voice	<input type="checkbox"/>			
Acknowledging Concerns	<input type="checkbox"/>			
Rephrasing or Changing Instructions When Needed	<input type="checkbox"/>			
Providing Helpful Feedback	<input type="checkbox"/>			
Being an Active Listener	<input type="checkbox"/>			
_____ (Other)	<input type="checkbox"/>			
Sum of scores for this domain ÷ # of tasks scored		____ ÷ ____	____ ÷ ____	____ ÷ ____
= COMMUNICATION SCORE (OVERALL SCORE Part B)				

Scale Definitions and Scoring Criteria for Parts A and C:

For each scale, select the score that best reflects the abilities of the person (care director or caregiver) or team (care director and caregiver working together), considering all behaviors observed over the past week. If performance varied during this period, select the score that best represents the **CURRENT** abilities of the care director, caregiver, or team. Mark "N/A" if a task does not require assistance from a caregiver or is not medically or functionally relevant to the person with tetraplegia.

Safety Scale: Addresses ability to direct or perform a care task in a manner that prevents illness or injury (physical, emotional, or financial) to the person receiving assistance or his/her caregiver.

Safety Scoring: How much of the care direction/caregiving is performed safely *without assistance* from the trainer?

1. None – Requires assistance from the trainer to direct or perform all of this task safely
2. Some – Able to direct or perform some of this task safely without assistance from trainer
3. Most – Able to direct or perform most of this task safely without assistance from trainer
4. All – Able to direct or perform all of this task safely without assistance from the trainer

Problem-Solving Scale: Relates to the ability to adjust how a task is directed or performed in response to unusual or challenging circumstances to maintain safety and/or increase efficiency.

Problem-Solving Scoring: How much of the problem-solving process can be done *without assistance* from the trainer?

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3. Most – Able to identify both problems and appropriate solutions but requires assistance from trainer to implement solutions
4. All – Able to identify problems and appropriate solutions, and can implement solutions without assistance from trainer

Scoring Criteria for Part B:

Communication Scale: Relates to the ability of the care director and caregiver to communicate effectively and appropriately with one another.

Communication Scoring: How much of the time is communication occurring in an appropriate manner *without assistance* from the trainer?

1. None – Unable to communicate effectively without assistance from trainer
2. Some – Able to communicate effectively *some* of the time without assistance from trainer
3. Most – Able to communicate effectively *most* of the time without assistance from trainer
4. All – Able to communicate effectively *all* of the time without assistance from trainer

TASKS – Part C (OPTIONAL for Pilot-Testing)		N/A	<u>Care Director</u>		&	<u>Caregiver</u>		=	<u>Team</u>	
			Safety	Problem-Solving		Safety	Problem-Solving		Safety	Problem-Solving
Home and Community Living (Domain 5)										
	Child Care (if applicable)	<input type="checkbox"/>								
	Pet Care (if applicable)	<input type="checkbox"/>								
	Maintaining a Clean and Healthy Home Environment	<input type="checkbox"/>								
	Food Preparation	<input type="checkbox"/>								
	Managing Legal/Financial Documents & Affairs	<input type="checkbox"/>								
	Transportation and Travel Planning	<input type="checkbox"/>								
	Work, School, or Leisure Activities	<input type="checkbox"/>								
	Performing Exercises for Strength or Fitness	<input type="checkbox"/>								
	Facilitating Intimate Relationships	<input type="checkbox"/>								
	_____ (Other)									
	Sum of scores for this domain ÷ # of tasks scored		____ ÷ ____	____ ÷ ____		____ ÷ ____	____ ÷ ____		____ ÷ ____	____ ÷ ____
	= HOME/COMMUNITY SCORE									
Managing Personnel (Domain 6)										
	Recruiting and Interviewing	<input type="checkbox"/>								
	Establishing Expectations and Policies	<input type="checkbox"/>								
	Coordinating Coverage and Schedules	<input type="checkbox"/>								
	Transitioning to New Staff as Needed	<input type="checkbox"/>								
	_____ (Other)									
	Sum of scores for this domain ÷ # of tasks scored		____ ÷ ____	____ ÷ ____						
	= MANAGEMENT SCORE									
	Sum of task scores in domains 5-6 ÷ # tasks scored		____ ÷ ____	____ ÷ ____						
	= OVERALL SCORE for Part C									

Do Not Score “Managing Personnel” Items in These Columns

These items will be scored only for the Care Director.

Use the HOME/COMMUNITY SCORE for Domain 5 as the OVERALL SCORE for Part C for the Caregiver and the Team.

Share your feedback!

Please use the space below (or email – see below) to note general comments or any difficulties you encountered in using the TEAM Tool. **When in doubt, fill out the form based on what feels most right to you and comment below about what you were uncertain about.** These could include difficulties deciding on a score, tasks that are not listed, areas where more guidance or clarity is needed in the instructions, etc. ANY ideas you may have for improving the content, format, or use of the TEAM Tool itself or the Instruction Manual are welcome.

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Thank you for your help!

Please return this form to the designated location for collection by the study team.

Appendix 13

Teaching Effective Assistance Management (“TEAM”) Tool Instruction Guide

(Post-Piloting Revised Version – Marked Changes and Clean Versions)

Teaching Effective Assistance Management (TEAM) Tool

Instruction Manual

Version Date ~~8/17/2016~~12/29/2017



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The creation of the TEAM Tool and Instruction Manual was supported by the Department of Defense Spinal Cord Injury Research Program under award number W81XWH-12-1-0553. Views and opinions of, and endorsements by, the authors do not reflect those of the US Army or the Department of Defense.

Special thanks are given to all members of the research team, our clinical colleagues, and to the organizations whose collaboration made this project possible.

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1. Overview of the TEAM Tool

The TEAM Tool provides information on the ability of people with tetraplegia due to spinal cord injury to appropriately direct their care and on the ability of caregivers to provide appropriate assistance. The TEAM Tool is completed based on observations of behavior that rehabilitation experts make in the process of training people with tetraplegia and their caregivers in direction of care and caregiving skills.

The TEAM Tool is designed to provide a comprehensive, high-level view of direction of care and caregiving ability. It is intended to complement, not replace, existing medical record documentation and other outcome measures that discuss the functional status of the person with tetraplegia or describe the specific content of training.

2. Background

Depending on the severity of the injury, people with tetraplegia due to spinal cord injury may require help from others to complete daily activities such as washing, moving from bed to chair, preparing food, and other important tasks. Appropriate assistance is critical to enable people with tetraplegia to participate in life activities and to prevent many of the health complications that can result from tetraplegia, such as pressure injury, pneumonia, and urinary tract infections.

Family members are often involved in providing care to people with tetraplegia. People with tetraplegia may also receive care from paid caregivers who are not nurses or otherwise formally trained in how to care for someone with tetraplegia. In order for people with tetraplegia to get the best possible care at home (rather than having to stay in a hospital or nursing home) it is important that they be able to tell someone when they need care and what needs to be done to help them (referred to as “direction of care”). It is also important that family members or others who are providing care to someone with tetraplegia learn how to properly perform these care tasks.

The process of learning to direct and provide care usually begins in acute inpatient rehabilitation. Clinicians and other rehabilitation professionals provide instruction about SCI and its consequences as well as hands-on training in directing care and providing assistance in tasks such as bowel and bladder care, transfers, bathing, range-of-motion exercises, and other activities. Ideally, people with tetraplegia and their caregivers are offered opportunities to practice directing and providing care, and receive feedback from rehabilitation professionals on their performance. Learning direction of care and caregiving skills continues after discharge as people with tetraplegia and their families continue rehabilitation in an outpatient setting and gain experience in the community.

While training in direction of care and caregiving is an important part of inpatient rehabilitation, current assessment tools and outcome measures provide no information on these skills. Commonly-used tools such as the Functional Independence Measure provide scores that are based on the level of independence of the person with tetraplegia. For skills that pertain to physical activity, such as transfers, these tools do not differentiate individuals who are actively engaged and in control of the task via verbal direction from those that are not participating in any way. Similarly, the quality of the assistance provided by the caregiver is not considered in the scoring of these tools. As a result, the rehabilitation field does not have a systematic (well-defined and consistent) way of describing how well someone can direct or provide care.

3. Anticipated Benefits of Using the TEAM Tool

The TEAM Tool is expected to enhance rehabilitation care by:

- Helping to identify training goals
- Documenting improvements in direction of care and caregiving skills over time, to provide justification for ongoing rehabilitation and to build confidence among those being trained
- Promoting conversations about difficult subjects such as care needs, willingness and ability of loved ones to provide care, interpersonal dynamics, etc.
- Facilitating discharge planning by helping clinicians assess and discuss readiness for discharge, identify areas in need of further training to prepare for discharge, etc.

The TEAM Tool is expected to enhance program evaluation and research by:

- Demonstrating the extent to which training programs improve direction of care and caregiving skills
- Facilitating assessment of relationships between direction of care/caregiving ability and important outcomes (such as complications, rehospitalizations, cost of care, and well-being)

4. Key Terms

Care director typically refers to the person with tetraplegia who is being trained to verbally instruct others in how to provide assistance. In cases where a person with tetraplegia is not being trained to direct care due to severe cognitive impairments or other issues, a family member or other responsible party may be trained to direct other caregivers (such as hired aides). In such cases, the responsible party is considered the care director.

Caregiver refers to a person who is being trained to provide assistance to the person with tetraplegia. The term “caregiver” is used in a broad sense, and may refer to paid or unpaid caregivers, including family members, friends, or staff that is hired privately or provided through an agency.

Team refers to the care director and caregiver working together as a unit. Because the dynamics between specific people are unique, each combination of care director and caregiver is its own “team.”

Trainer refers to a clinician, rehabilitation professional, or other “expert” (such as an experienced peer educator) who provides training in direction of care and caregiving skills in a rehabilitation context.

Task refers to an activity or (more commonly) a set of activities related to a particular objective (such as proper body positioning) or area of functioning (such as eating and drinking). Each person with tetraplegia has a unique combination of needs and preferences. Therefore, the specific tasks to be performed will vary from person to person. Other forms of documentation, such as the medical record or checklists for caregivers, can provide detail on the specific tasks to be performed for a particular person with tetraplegia. The types of activities included in each task (the “scope” of the task) is defined in Section 6 below.

Scale refers to a way of “measuring” a particular aspect of care direction and/or caregiving performance. The TEAM Tool includes three scales: *Safety*, *Problem-Solving*, and *Communication*. Because these scales represent distinct concepts, scores are calculated separately for each scale using different scoring criteria.

Domain refers to a collection of tasks that relate to a larger goal or activity. The TEAM Tool provides information on six domains: Preventing Complications, Mobility in Daily Life, Other ~~Daily~~ Activities, Communicating Effectively, Home and Community Living, and Managing Personnel.

Domain Score refers to a score that is calculated within a particular domain, based on scores for all applicable tasks within that domain. Domain Scores are calculated separately for the Safety, Problem-Solving, and Communication scales.

Overall Score is calculated for each part (A, B, C) of the TEAM tool based on *all* the scores recorded for the tasks listed within a particular part (A, B, or C) of the form. Overall scores are calculated separately for the Safety, Problem-Solving, and Communication scales.

5. Structure of the TEAM Tool

Listing of Tasks

The TEAM Tool consists of three parts, organized by the nature of the tasks included in each part.

- **Part A** focuses on tasks that are fundamental to health and/or everyday functioning for which direction of care/caregiving training typically begins in an inpatient setting.
- **Part B** addresses communication-related behaviors that are observed by trainers as people with tetraplegia and their caregivers practice direction of care or providing care during training.
- **Part C** addresses more advanced skills related to maintaining one’s home, participating in community activities, and managing hired staff (if applicable). The tasks in Part C are included because they are considered important to people with tetraplegia and are needed for success in community life on the long-term. However, depending on the care setting, these areas may not be addressed in inpatient rehabilitation. Training may occur in outpatient rehabilitation in the context of other programs offered post-discharge. These advanced skills are therefore placed in a separate section of the TEAM Tool, but may be scored by inpatient trainers if they are addressed in training.

Separate Scoring for Care Director, Caregiver, and Team

Within each part of the TEAM Tool, scores are given separately for the care director, caregiver, and for the team (care director and caregiver working together). This approach to score assignment is designed to reflect that the success of a caregiving experience involves contributions from both members of the care team, who may differ in their levels of ability. This approach also provides flexibility, allowing the TEAM Tool to be utilized with the person with tetraplegia who is receiving training even if the caregiver has not yet been identified or is unable to attend training.

6. Scope of Tasks

For all domains, an “other” field is available on the form to provide trainers the option of adding another task that is relevant to the person with tetraplegia but is not already listed.

Part A

Domain 1. Preventing Complications

1. Using Ventilator Properly. Includes ability to keep ventilator fully powered, properly maintained, and functioning at the correct settings as well as implementing emergency measures in case of a ventilator failure (including using manual bagging to maintain breathing and contacting appropriate people for help). May include use of supplemental oxygen if prescribed.

2. Keeping Airways Clear. Includes suctioning, assisted coughs, tracheostomy care, adherence to swallowing-related precautions, and other measures taken to prevent secretions or food/liquids from interfering with breathing.”

~~1. Maintaining Breathing. Includes ability to keep ventilator fully powered, properly maintained, and functioning at the correct settings as well as implementing emergency measures in case of a ventilator failure (including using manual bagging to maintain breathing and contacting appropriate people for help). Also includes suctioning, assisted coughs, tracheostomy care, adherence to swallowing-related precautions, and other measures taken to prevent secretions or food/liquids from interfering with breathing. May include use of supplemental oxygen if prescribed.~~

2.3. Managing Blood Pressure. Includes any actions taken to prevent a problematic drop or increase in blood pressure. Such actions may include use of stockings, abdominal binders, or other aids to help maintain pressure; medications to manage blood pressure; care with position changes to avoid sudden drop in blood pressure, and other actions.

4. Responding to Autonomic Dysreflexia. Includes recognizing signs of autonomic dysreflexia, taking actions to stop the dysreflexia (sitting up, emptying bladder, loosening clothing, using medication, etc.), and seeking emergency assistance if needed.

3.5. Maintaining Healthy Skin. Includes appropriate cleaning/rinsing of skin via a shower or bed bath, thoroughly drying the skin, applying lotion, handling the skin gently to avoid irritation or damage, and other actions needed to ensure skin remains clean, dry, and free of injury. Also includes inspecting skin in a manner that would allow signs of skin damage to be seen (such as using appropriate lighting, looking at all areas at risk), identifying areas that suggest a problem may be developing (such as pressure injury), and identifying appropriate actions to take to respond to what

is found during inspection (adjusting sitting time or frequency of repositioning, contacting physician, etc.).

- ~~4. Properly Cleaning and Caring for Skin. Includes appropriate cleaning/rinsing of skin via a shower or bed bath, thoroughly drying the skin, applying lotion, handling the skin gently to avoid irritation or damage, and other actions needed to ensure skin remains clean, dry, and free of injury.~~
- ~~5. Detecting/Responding to Signs of Skin Problems. Includes inspecting skin in a manner that would allow signs of skin damage to be seen (such as using appropriate lighting, looking at all areas at risk), identifying areas that suggest a problem may be developing (such as pressure injury), and identifying appropriate actions to take to respond to what is found during inspection (adjusting sitting time or frequency of repositioning, contacting physician, etc.).~~
6. Emptying Bowels Regularly. Includes implementation of the prescribed bowel program. This includes use of medications or supplements, enemas or mini-enemas, suppositories, stimulation with one's finger or a device, and other actions required so that all stool is removed from the bowel. Also includes correct assessment of when bowels are empty and performance of bowel emptying techniques with appropriate hand hygiene/glove use, and in a manner that reduces the likelihood of injuring the anus, rectum, or other bowel structures. May include proper colostomy use if applicable. Also includes ability to identify when a bowel problem may require further intervention by a physician or other health care professional.
7. Emptying Bladder Regularly. Includes implementation of all actions required to ensure that the bladder is emptied completely and regularly. Includes proper hand hygiene, glove use, cleansing of skin in the areas where bladder emptying is occurring, and handling of supplies to prevent infection. Also includes correct use of bladder medications, catheters, physical techniques to induce urination (such as applying pressure), as prescribed. Also includes ability to identify when intervention by a physician or other health care professional may be required to address a possible infection or other issue (as indicated by the amount, odor, color, cloudiness of urine).
8. Using Medications as Prescribed. Pertains to taking medications at appropriate times and dosages, including ability to identify potential side effects and take action to follow-up on medication-related issues.
9. Proper Body Positioning. Includes static positioning in bed and wheelchair. May include supporting shoulders to avoid dislocation, preserving tightness in hands when needed for grasping objects (tenodesis), positioning body to avoid excessive pressure, ensuring ability to reach bed or chair controls independently (if applicable), using splints or other devices to help hold the body in the correct position, and other actions required to keep the person with tetraplegia's body in a position that prevents complications (including pain, skin damage, range of motion problems, falls) and maximizes their ability to function.
- 8-10. Shifting Weight Regularly. Includes all aspects of directing or performing weight-shifting in bed or wheelchair, including performance on an appropriate schedule, correct duration of shift, correct use of technology to assist with shifting (such as controls for tilting), use of an appropriate variety of shifting techniques, and performing shifts in a manner that would avoid acute or chronic injury to the person with tetraplegia or his/her caregiver.

~~9. Taking Precautions Against Infection. Includes actions taken to avoid infection in any part of the body. Includes proper hand hygiene, cleaning or sanitizing of equipment that could spread infection (such as leg bags), appropriate handling and storage of equipment, etc. *Note: This task may overlap with others where proper execution of the task includes steps to prevent infection (such as maintaining breathing, emptying bladder regularly).* Behaviors that relate both to infection control and to the performance of another task may be considered in the scoring of both tasks.~~

~~10. Proper Body Positioning in Bed. Includes both static positioning in bed and turning techniques. May include supporting shoulders to avoid dislocation, preserving tightness in hands when needed for grasping objects (tenodesis), positioning body to avoid excessive pressure, ensuring ability to reach bed controls independently (if applicable), using splints or other devices to help hold the body in the correct position, and other actions required to keep the person with tetraplegia's body in a position that prevents complications (including pain, skin damage, range of motion problems, falls) and maximizes their ability to function.~~

~~11. Proper Body Positioning in Wheelchair. Includes both static sitting and weight-shifting techniques. May include supporting shoulders to avoid dislocation, preserving tightness in hands when needed for grasping objects (tenodesis), positioning body to avoid excessive pressure, ensuring ability to reach wheelchair controls independently (if applicable), using splints or other devices to help hold the body in the correct position, and other actions required to keep the person with tetraplegia's body in a position that prevents complications (including pain, skin damage, range of motion problems, falls) and maximizes their ability to function.~~

~~12.11. Performing Range of Motion. Includes performance of exercises to prevent loss of motion in arms, legs, hands, or other body parts. Technique of moving and monitoring for signs of problems (such as grimacing, increase spasticity, etc.) may be considered in scoring.~~

Domain 2. Mobility in Daily Life

~~13. Transfers Between Level Surfaces. Includes all aspects of directing/performing transfers between surfaces that are level or uneven (except for floor to chair transfers or other transfers intended for emergency use). Includes transfers to and from bed, wheelchair, commode/shower chair, and car. Includes appropriate use of equipment, appropriate set-up of the surfaces involved in the transfer, receiving/providing assistance as needed to perform the transfer and avoid a fall, etc.* Includes all aspects of directing/performing transfers *between surfaces that are level*. Typically includes transfers between bed, wheelchair, and commode/shower chair, as long as both transfer surfaces are level with one another. Includes appropriate use of equipment, appropriate set-up of the surfaces involved in the transfer, receiving/providing assistance as needed to perform the transfer and avoid a fall, etc.~~

~~12.~~

~~14. Transfers Between Uneven Surfaces.* Includes all aspects of directing/performing transfers *between surfaces that are uneven (not level with one another)*. Includes car transfers but excludes floor to chair transfers, which are covered under Emergency Transfers below). May include transfers between other surfaces (bed, wheelchair, commode/shower chair) if the transfer surfaces are not level with one another.~~

~~* When determining whether to score a particular transfer as part of Transfers Between Level Surfaces or Transfers Between Uneven Surfaces, remember that the key element is the "level-ness"~~

~~of the transfer, not the types of surfaces involved (bed, wheelchair, shower chair, etc.). When in doubt, include a transfer you consider to be more difficult under Uneven Surfaces rather than Level Surfaces.~~

- ~~15-13. Emergency Transfers.~~ Pertains to transfers that may be needed in case of emergency, such as getting up from the floor or getting out of the chair quickly in case of malfunction or emergency requiring evacuation outside of the chair.
- ~~14. Moving Around in Bed.~~ Includes receiving/providing appropriate assistance to move from sitting to supine (laying), rolling, scooting, etc.
- ~~16. Moving Around by Wheelchair.~~ Includes directing/providing appropriate assistance to move via wheelchair over level or uneven surfaces such as floors, ramps, and grass. Also includes using doors, elevators, and wheelchair lifts. Excludes curbs or stairs. When scoring, consider guarding techniques, cueing or assistance for maneuvers in tight spaces, and ability to use manual mode if needed for power chair users. Mark this task Not Applicable if the person with tetraplegia will walk as their primary mode of mobility, and use the "Other" task in this section to rate direction of care and assistance provided in relation to walking.
- ~~15.~~
- ~~17. Mobility (Walking or Wheelchair) on Flat Surfaces.~~ Includes receiving/providing appropriate assistance to move (via wheelchair or walking) over level surfaces. Typically includes interior floors but may also include paved outdoor surfaces if they are smooth. Includes guarding techniques, cueing or assistance for maneuvers in tight spaces, use of manual mode for power chair users.
- ~~18. Mobility (Walking or Wheelchair) on Uneven Surfaces.~~ Includes receiving/providing appropriate assistance to move (via wheelchair or walking) over uneven surfaces, such as grass, ramps, wheelchair lifts, curbs, stairs (as applicable to the person receiving assistance). Includes guarding techniques, cueing or assistance to maneuver in tight spaces, use of manual mode for power chair users.
- ~~19-16. Managing Wheelchair Parts.~~ Includes manipulating parts of the wheelchair to allow for transfers, wheeling or driving the chair, storage or transport of the chair. Includes moving and positioning armrests, footrests, headrest, drive control, or other parts. For manual wheelchair users, includes removing and replacing wheels and folding the chair (if applicable). For power wheelchair users, includes charging the chair but excludes driving it into a vehicle (which would be considered part of Walking or Wheeling on Uneven Surfaces above).

Domain 3. Other ~~Daily~~ Activities

- ~~20-17. Eating and Drinking.~~ Includes directing a caregiver and/or providing assistance in bringing food and drink to the mouth. Excludes cooking and food selection. Includes positioning the person with tetraplegia appropriately (to prevent food going into the airway, enable him/her to hold/reach utensils, cups, etc.), providing food in appropriate bite sizes and at an appropriate rate, etc.
- ~~21-18. Bathing.~~ Includes directing a caregiver or providing assistance in washing body and hair via shower, bed bath, or other means. Excludes transfers involved in bathing, which are covered under either Transfers Between Level Surfaces or Transfers Between Uneven Surfaces depending on the

setup.

22.19. Grooming. Includes washing face and hands, brushing and flossing of teeth, shaving, styling hair and (if applicable) applying makeup in the manner preferred by the person receiving assistance.

20. Dressing. Includes dressing of the upper and lower body in a manner that avoids complications (as might occur from clothing or shoes that are too tight) and achieves the appearance desired by the person receiving assistance.

21. Phone and Computer Access. Includes directing/providing assistance with use of a telephone (land-line or cellular), tablet, laptop computer, desktop computer, or other electronic device used for communication, information access, control of environment, or other purposes. *Note: This task may overlap with others that involve phone or computer use, such as Work, School, or Leisure Activities. Behaviors that relate both to phone/computer use and to the performance of another task may be considered in the scoring of both tasks.*

22. Maintaining Stock of Supplies. Includes directing/providing assistance with inventory of medical and household supplies, ordering, and organization of supplies once received.

23. Maintaining Equipment. Includes directing/providing assistance with inspecting equipment (wheelchairs, cushions, shower chair, commode, mattress, etc.) for signs of wear and tear or malfunction, cleaning equipment (to maintain its appearance and/or function), making arrangements for routine checks or repairs by technicians when appropriate.

23.——

Part B

Domain 4. Communicating Effectively

24. Using Appropriate Language Words and Tone of Voice. Includes addressing the other member of the care team (care director or caregiver) using their preferred title or name, expressing gratitude, avoiding negative words or insults. Also includes speaking at a volume and pace that is conducive to understanding, using a tone that is appropriate to the situation. Also includes non-verbal aspects of communication, such as eye contact, smiling (when appropriate), avoiding negative gestures or actions (sighs, groans, eye-rolling, etc.). ~~Includes addressing the other member of the care team (care director or caregiver) using their preferred title or name, expressing gratitude, avoiding negative words or insults.~~

25. Using Appropriate Tone of Voice. Includes speaking at a volume and pace that is conducive to understanding, using a tone that is appropriate to the situation. Also includes non-verbal aspects of communication, such as eye contact, smiling (when appropriate), avoiding negative gestures or actions (sighs, groans, eye-rolling, etc.)

25. Detecting/Responding to Misunderstanding or Uncertainty Acknowledging Concerns. Includes ability to recognize when there is a concern, misunderstanding, or other issue and speaking up about it before a problem occurs. Signs of misunderstanding may include hesitance in speaking or performing a task, or actions or gestures (such as furrowed brow, sighs, groans, frown, unusual silence, etc.). Appropriate acknowledgements of the concern might include asking the other

member of the team if he/she has a question about what is being done, stopping the action to point out something that needs to be done differently, asking the other member of the team if additional or different instructions would be helpful, etc.

~~26. Includes ability to recognize when the other member of care team is uncertain about what to do or may have misunderstood what has been said and then taking appropriate actions to clarify what is needed. Signs of misunderstanding may include hesitance in speaking or performing a task, or actions or gestures (such as furrowed brow, sighs, groans, frown, unusual silence, etc.). Indicators that the care director or caregiver is appropriately detecting and responding to uncertainty include confirming an instruction or request, adding clarification, asking if additional or different instructions would be helpful, etc.~~

~~27.~~

~~28.~~26. Rephrasing or Changing Instructions When Needed. Includes ability to use different words or other techniques (such as demonstration--when feasible, reference to a document, picture, or video, etc.) to help the other member of the care team understand what is being said or requested.

~~29. Speaking up for Needs or Concerns. Includes the extent to which members of the team speak up when they have a question or concern, rather than allowing someone else to speak for them or not speaking until after a problem occurs.~~

~~30.~~27. Providing Helpful Feedback. Includes telling the other member of the care team what worked well and what did not in the care interaction, using language that is respectful and non-accusatory in tone.

~~31.~~28. Being an Active Listener. Includes behaviors such as making eye contact, allowing the speaker to speak without interruptions (except when needed to clarify what is being said), restating what was said to make sure it was understood, etc.

Part C

Domain 5. Home and Community Living

~~32.~~29. Child Care. Includes directing/providing assistance with addressing the child's basic needs (bathing, food, clothing, diapering, toileting) as well as participating in activities together (games, homework, etc.)

~~33.~~30. Pet Care. Includes directing/providing assistance with addressing the pet's basic needs (feeding, taking care of waste, cleaning/grooming, other aspects of maintaining the health and well-being of a pet), as well as participating in activities together.

~~34.~~31. Maintaining a Clean and Healthy Home Environment. Includes assistance related to house cleaning as well as laundry.

~~35.~~Food Preparation. Includes assistance with shopping, meal planning, cooking, storage/packaging of food, etc.

~~32.~~

~~36. Phone and Computer Access. Includes directing/providing assistance with use of a telephone (land-line or cellular), tablet, laptop computer, desktop computer, or other electronic device used for communication, information access, control of environment, or other purposes. Note: This task~~

~~may overlap with others that involve phone or computer use, such as Work, School, or Leisure Activities. Behaviors that relate both to phone/computer use and to the performance of another task may be considered in the scoring of both tasks.~~

~~37. Managing Legal/Financial Documents and Affairs.~~ Includes directing/providing assistance with handling of mail, bills, banking, and other affairs.

~~33.~~

~~38. Maintaining Stock of Supplies.~~ Includes directing/providing assistance with inventory of medical and household supplies, ordering, and organization of supplies once received.

~~39. Maintaining Equipment.~~ Includes directing/providing assistance with inspecting equipment (wheelchairs, cushions, shower chair, commode, mattress, etc.) for signs of wear and tear or malfunction, cleaning equipment (to maintain its appearance and/or function), making arrangements for routine checks or repairs by technicians when appropriate.

~~40.~~ 34. Transportation and Travel Planning. Includes directing/providing assistance with packing appropriate supplies, verifying accessibility of transportation and lodging, managing time to ensure on-time arrival, etc.

~~41.~~ 35. Work, School, or Leisure Activities. Includes directing/providing assistance with activities specifically related to taking classes, performing job functions, participating in recreational activities, etc.

~~42.~~ Performing Exercises for Strength or Fitness. Includes proper performance of recommended home exercises such as functional electrical stimulation cycling, strengthening exercises, etc.

~~36.~~

~~43.~~ 37. Facilitating Intimate Relationships. Includes working with a caregiver to prepare for sexual activities, including appropriate positioning, adjustment of catheters or other equipment, contraceptive use, etc.

~~44. Accessing Resources When Needed.~~ Includes recognizing when outside assistance may be needed (from equipment supplier, clinician, other members of support system), working with caregivers to identify an appropriate source of assistance and the best way of contacting that source, and effectively communicating with that resource to obtain the needed assistance.

Domain 6. Managing Personnel

Note: Tasks in this section apply only to those who be using the services of hired caregivers. Only the care director's performance is scored in this section.

~~45.~~ 38. Recruiting and Interviewing. Includes advertising for help, scheduling interviews, conducting interviews.

~~46.~~ 39. Establishing Expectations and Policies. Includes describing care needs, setting rules of conduct, etc.

~~47.~~40. Coordinating Coverage and Schedules. Includes setting schedule for caregivers and communicating that to others as needed; identifying backup plan in case of staff illness or other issue.

~~48.~~41. Transitioning to New Staff as Needed. Includes communicating intent to terminate work relationship, preparation of documents, etc.

7. Scoring Criteria

Scores are given for care directors, caregivers, and the care team for three different scales: Safety, Problem-Solving (Parts A and C only), and Communication (Part B only). These scales reflect different aspects of direction of care or caregiving performance. The scores for each scale reflect the extent to which the care director, caregiver, or team are able to appropriately execute that aspect of task performance without assistance from the trainer. Assistance may include physical help, cueing or reminders given via words or gestures, responding to questions asked by the care director or caregiver, or other forms of help. Descriptions of each scale and their scoring criteria are given below:

Safety Scale: Addresses ability to direct or perform a care task in a manner that prevents illness or injury (physical, emotional, or financial) to the person receiving assistance or his/her caregiver.

Safety Scoring: How much of the care direction/caregiving is performed safely *without assistance* from the trainer?

1. None – Requires assistance from the trainer to direct or perform all of this task safely
2. Some – Able to direct or perform *some* of this task safely without assistance from trainer
3. Most – Able to direct or perform *most* of this task safely without assistance from trainer
4. All – Able to direct or perform *all* of this task safely without assistance from the trainer

Problem-Solving Scale: Relates to the ability to adjust how a task is directed or performed in response to unusual or challenging circumstances to maintain safety and/or increase efficiency.

Problem-Solving Scoring: How much of the problem-solving process can be done *without assistance* from the trainer?

1. None – Requires complete assistance from trainer to identify problems and implement solutions
2. Some – Able to identify problems, requires assistance from trainer to identify and implement solutions
3. Most – Able to identify both problems and appropriate solutions but requires assistance from trainer to implement solutions
4. All – Able to identify problems and appropriate solutions, and can implement solutions without assistance from trainer

Communication Scale: Relates to the ability of the care director and caregiver to communicate effectively and appropriately with one another.

Communication Scoring: How much of the time is communication occurring effectively *without assistance* from the trainer?

1. None – Unable to communicate effectively without assistance from trainer
2. Some – Able to communicate effectively *some* of the time without assistance from trainer
3. Most – Able to communicate effectively *most* of the time without assistance from trainer
4. All – Able to communicate effectively *all* of the time without assistance from trainer

Note that “None” and “All” should be interpreted as “nearly none” and “nearly all.” A score of “None” may still be given if a task is done without help but only on rare occasions. Similarly, a score of “All” may

still be given if occasional errors are made but are self-corrected (therefore not requiring assistance) or if assistance is needed on rare occasions or when there are very unusual circumstances.

There is not a strict percentage associated with “some” or “most”—we leave it to the judgment of the trainer to determine which score best characterizes the ability of the care director, caregiver and or team being scored.

8. General Principles for Completing the TEAM Tool

Scores are based on observations of care director and caregiver behavior made by the trainer(s) during training. The TEAM Tool is designed to be completed by rehabilitation professionals (or other “trainers” as defined above) based on observations that they make during the process of training people with tetraplegia to direct their care and training family members or others to perform care tasks (such as assisting with a transfer or catheterization). Scores should be based on behaviors observed during practice of direction of care or caregiving whenever possible, to the extent that practice of these tasks occurs in typical clinical care.

For those tasks that are not feasible to practice in clinical care (such as responding to autonomic dysreflexia) an assessment may be made via a discussion of how the person with tetraplegia would direct the task or how his/her caregiver would perform the task. (It is anticipated that most of the tasks in Part C, which involves community skills and personnel management, will need to be assessed in this manner.)

It is not necessary for the person with tetraplegia AND his/her caregiver to be present for an assessment to take place—in the event that a caregiver is not present or available, a rehabilitation staff member may serve as the caregiver, with direction of care provided by the person with tetraplegia.

Scores are only given for tasks that *involve the assistance of a caregiver*. The TEAM Tool is designed to provide information about direction of care and caregiving ability. Any task that the person with tetraplegia is able to do on his/her own (or is being trained to do on his/her own) should not be scored.

For example, a person with tetraplegia may be trained to drive a power wheelchair over flat surfaces. If the goal of training is for the person with tetraplegia to be able to perform this task without any assistance (supervision, cueing or physical assistance) from a caregiver, then this task should be marked “Not applicable” and should not be scored in the TEAM Tool.

If however, the expectation is that the person with tetraplegia will utilize supervision, cueing, or other assistance from a caregiver for power wheelchair driving over level surfaces post-discharge, this task should be scored.

No changes in typical clinical care are required for the TEAM Tool to be completed. The TEAM Tool is intended to assist the process of training people with tetraplegia and their caregiver by encouraging evaluation of these skills by the rehabilitation team, and providing a mechanism for documenting and communicating assessment findings. The TEAM Tool may “inspire” changes to the training process by drawing attention to areas in which training is needed, but changes in typical care are NOT required for the team tool to be completed.

Decisions about what skills to train, how to train them and when to provide training should be driven by clinical considerations and not by the need to complete the tool. Clinicians may choose to incorporate

the tool in their training efforts in whatever ways feel most appropriate, including reviewing it with patients/caregivers during training, discussing with other members of the patient's clinical team, etc.

Any trainer may score performance in any task that he/she observes. While the scope of practice differs among clinical disciplines (occupational therapy, physical therapy, nursing, etc.), there is often overlap between disciplines in the topics of training. For example, both nurses and occupational therapists may provide education related to intermittent catheterization. For purposes of pilot-testing, any trainer may score any task that is considered part of his/her training activities, regardless of his/her clinical discipline. *(Note: These instructions may be changed in future pilot-testing to have scoring divided among clinical team members.)*

Scores are based on observations made during a one week look back period. Scores given on the TEAM Tool are based on observations of behavior made in the week prior to (and including) the date the trainer is completing the tool. A look back period of this length is provided to maximize opportunities to observe various skills, since it is rarely feasible to observe all skills in a single day or even over 2-3 days. It also gives trainers flexibility to complete the tool when their schedules permit.

Scores should be given based on the trainer's assessment of the CURRENT abilities of the care director or caregiver. For tasks that are performed multiple times during the look back period, performance may vary over the course of the week. The trainer should pick the score that he/she feels best reflects the abilities of the care director or caregiver as of the date the TEAM Tool is being completed.

For example, in a situation where performance improved over the course of the week, and less help was needed from the trainer, the score given on the TEAM Tool should be based on the more recent observations.

In other situations, performance may be inconsistent, such that lot of help from the trainer is needed on some days and little on others, with no discernable trend of improvement. In such a case, it may be more appropriate to give a score that reflects the poorer performance, even if little help was needed at the most recent observation. If inconsistency of performance is related to task setup (an "idealized" setup vs. one closer to that of the home environment) scoring should be based on the setup that is closest to that of the home environment.

Trainers should assign scores based on the perceived need for assistance, even if assistance was not actually provided. There may be circumstances in which assistance may be needed but is not actually given. For example, a care director and caregiver may be communicating inappropriately early in the training process but the trainer has not yet developed the rapport necessary to intervene productively. In such situations, the trainer should assign a score based on the assistance he/she would have provided if circumstances permitted.

The TEAM Tool is designed to be completed at multiple points in time. The TEAM Tool is designed to be used at multiple time-points so that changes in skill level can be documented over time. The tool may be completed as often as deemed appropriate by the trainer(s). For purposes of pilot testing, the target windows for completion of the tool are:

- Within two weeks of admission to inpatient rehabilitation *(Note: This instruction may be changed in future pilot-testing based on feedback indicating that it may be most productive to review the tool's content in this window, but defer initial scoring until later.)*

- Near the midpoint of the inpatient rehabilitation stay (the middle two weeks of the stay, based on the best available information about anticipated discharge date)
- Within two weeks prior to discharge

If completion of the tool within these windows is not feasible, the research team will consult with trainers to identify appropriate timeframes.

9. Step-By-Step Instructions for Pilot-Testing of the TEAM Tool

1. **Select a day** within the target window to complete the TEAM Tool and obtain a TEAM Tool form. (Research staff will notify you of the window dates and will provide copies of the forms.)
2. **Fill out the date and ID fields** on the first page (research staff can fill in the remaining pages for you, unless you prefer to label them yourself).
 - ☐ Enter your clinician ID. IDs will be provided by the research staff.
 - ☐ Write the assessment date, which is the date on which you are completing the assessment form. All scores should be entered on the same day, based on observations made during care director and caregiver training during the week prior to (and including) the date on which you are completing the form. This period is referred to as the **look back period**.
 - ☐ Write the ID of the person with tetraplegia who is being trained. IDs will be provided by the research staff.
 - ☐ If a caregiver was trained during the look back period, enter the ID for that caregiver (also provided by research staff). Only one pairing of care director and caregiver should be assessed on a single TEAM Tool form. If more than one caregiver was trained during the look back period, enter the ID for the person who is most likely to be the primary caregiver and base your scores on the performance of this care director-caregiver team. (You may complete additional TEAM Tool forms for other caregivers if you wish, but this is optional.) If no caregiver was trained during this week, and you served the role of the caregiver during direction of care training, leave the caregiver ID blank.
3. **Complete scores for the tasks presented in Parts A and B.** For each task:
 - ☐ Determine if the task applies to the person with tetraplegia. Mark the task “NA” (not applicable) if:
 - It is not medically or functionally relevant to the person with tetraplegia (such as “Managing Wheelchair Parts” for someone who not a wheelchair user)
 - It does not require the assistance of a caregiver [such as “Mobility (Walking or Wheelchair) on Flat Surfaces” in the case of a person with tetraplegia who is being trained to be independent in power wheelchair mobility]
 - ☐ If the task is applicable, assign scale scores (Safety and Problem-Solving for Part A, Communication for Part B) as follows:
 - Use the scoring criteria on the bottom of page 2 of the TEAM Tool (and also described in this manual on page 13 to guide your scores.
 - Enter scores in the columns relevant to those who received training in the task during the look back period:
 - Blue column only: Only the care director (person with tetraplegia) received training

- Blue and yellow columns: Care director and caregiver received training, but did not practice performing a task together
 - Blue, yellow, and green columns: If both a care director and caregiver were trained and they practiced one or more tasks in that area together
 - A formal assessment is not necessary to enter a score of 1 (None) in any column—if the person (or team) being assessed has not received training or has not yet been asked to demonstrate any tasks within that area, enter a score of 1, indicating that they are not yet able to do any tasks in the task without assistance.
 - ⊖ Leave a task blank only if it falls outside the scope of your practice (meaning that you do not provide any training relevant to this area and do not have expertise required to evaluate the performance.) If you wish, you may enter a dash in the box rather than leaving it blank. *(Note: These instructions may be changed in future pilot-testing if scoring is divided among clinical team members.)*
 - Note that while inter-personal issues are often addressed by a psychologist, the tasks in the domain of Communicating Effectively are considered to be within the scope of all disciplines.
 - If there is another task in a domain that is relevant to the person with tetraplegia but is not addressed in other tasks (such as wound care), write this task on the line marked “_____ (Other)” and assign scores as discussed above.
4. **(Optional) Complete scores for the tasks presented in Part C.** The tasks in Part C are considered more advanced or otherwise may fall outside the scope of what is typically covered in inpatient rehabilitation, therefore this section is optional. It is included in recognition of the importance of these skills for long-term success in the community and to prepare for later piloting of the tool in settings beyond inpatient rehabilitation. If you choose to complete Part C, please follow the instructions listed in item 3 above for Parts A and B. *(Note: These instructions may change in future pilot-testing that involves use of the tool beyond inpatient rehabilitation.)*
5. **Calculate Domain Scores.** *(If pressed for time, you may leave this to research staff to complete for you.)* Domain scores are calculated for each of the six domains: (Preventing Complications, Mobility in Daily Life, Personal Health and Appearance, Communicating Effectively, Home and Community Skills, Personnel Management Skills). Within each of these six domains, calculate domain scores for each column as follows:

Domain score = $X \div Y$

Where: X = Sum of the scores given to the tasks within the domain
(Enter this in the first blank of the “__ ÷ __” in the column)

Y = Number of tasks scored (not marked N/A or left blank) in the domain
(Enter this in the second blank in the “__ ÷ __” in the column)

If no scores appear in a particular column, leave the Domain Score lines blank.

6. **Calculate Overall Scores for Parts A, B, and C.** (You may leave this to research staff to complete for you.) Within each Part, calculate overall scores for each column as follows:

$$\text{Overall score} = P \div Q$$

Where: P = Sum of the scores given to the tasks within the Part
(Do not include the Domain Scores you calculated, only the scores for the tasks themselves. Enter in the first blank of the “__ ÷ __” in the Overall Score row.)

Q = Number of tasks scored in that Part
(Enter in the second blank in the “__ ÷ __”)

If no scores appear in a particular Part, leave the Overall Score lines blank.

7. **Note feedback on your experiences using the tool.** Space is provided on page 4 of the TEAM Tool packet for you to share comments about difficulties with scoring, tasks that were not included, uncertainties in the instructions, etc. The purpose of pilot-testing is to identify what works well and what does not, so all feedback is welcome.
8. **Return form to designated location for collection by the research team.** A member of the research team will collect the forms on a regular basis.

9. Resources on Care Direction and Caregiving
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<u>Title/Description</u>	<u>Accessible/Downloadable From</u>
A Step-by-Step Guide to Training and Managing Personal Assistants: Consumer Guide)	http://familyserviceswe.ca/sites/default/files/documents/a%20step-by-step%20guide%20to%20training.pdf
How to Successfully Hire and Manage a Personal Care Assistant: For People with Spinal Cord Injury (also available as iBook)	http://www.sfphysio.fr//docs/2015131740_how-to-successfully-hire-and-manage-a-personal-care-assistant-for-people-with-spinal-cord-injury.pdf
Managing Personal Assistants: A Consumer Guide (PVA)	http://www.pva.org/atf/cf/%7BCA2A0FFB-6859-4BC1-BC96-6B57F57F0391%7D/persasstfc6d.pdf
Personal Care Assistance: How Much Help Should I Hire	https://craighospital.org/resources/personal-care-assistance-how-much-help-should-i-hire
Personal Care Assistants: How to Find, Hire, & Keep	https://craighospital.org/resources/personal-care-assistants-how-to-find-hire-keep
Long Term Caregivers: For Better and For Worse	https://craighospital.org/resources/long-term-caregivers-for-better-and-for-worse
As the Years Go By: Accepting New Help	https://craighospital.org/resources/as-the-years-go-by-accepting-new-help
Video: Perspectives From Those Providing Care	http://sci.washington.edu/care_providers/index.asp
Video: Managing Personal Caregivers: A Panel Discussion	http://sci.washington.edu/caregivers/index.asp
Video: Personal Caregivers: Tips, Tricks and Tales from Individuals with Spinal Cord Injury	http://sci.washington.edu/info/forums/reports/caregivers.asp
SCI Forum Report – Personal Care Attendants	http://sci.washington.edu/info/forums/reports/attendant.s.asp
The Rough Guide to Managing Personal Assistants	http://www.independentliving.org/docs6/vasey2000.html
Caring for Caregivers – SCI InfoSheet	http://www.spinalcord.org/resource-center/askus/index.php?pg=kb.page&id=299
Long Term Caregivers: For Better and For Worse	https://craighospital.org/resources/long-term-caregivers-for-better-and-for-worse
Hiring In-Home Help – Family Caregiver Alliance	https://www.caregiver.org/hiring-home-help

***Teaching Effective Assistance Management
(TEAM) Tool***

Instruction Manual

Version Date 12/29/2017



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The creation of the TEAM Tool and Instruction Manual was supported by the Department of Defense Spinal Cord Injury Research Program under award number W81XWH-12-1-0553. Views and opinions of, and endorsements by, the authors do not reflect those of the US Army or the Department of Defense.

Special thanks are given to all members of the research team, our clinical colleagues, and to the organizations whose collaboration made this project possible.

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1. Overview of the TEAM Tool

The TEAM Tool provides information on the ability of people with tetraplegia due to spinal cord injury to appropriately direct their care and on the ability of caregivers to provide appropriate assistance. The TEAM Tool is completed based on observations of behavior that rehabilitation experts make in the process of training people with tetraplegia and their caregivers in direction of care and caregiving skills.

The TEAM Tool is designed to provide a comprehensive, high-level view of direction of care and caregiving ability. It is intended to complement, not replace, existing medical record documentation and other outcome measures that discuss the functional status of the person with tetraplegia or describe the specific content of training.

2. Background

Depending on the severity of the injury, people with tetraplegia due to spinal cord injury may require help from others to complete daily activities such as washing, moving from bed to chair, preparing food, and other important tasks. Appropriate assistance is critical to enable people with tetraplegia to participate in life activities and to prevent many of the health complications that can result from tetraplegia, such as pressure injury, pneumonia, and urinary tract infections.

Family members are often involved in providing care to people with tetraplegia. People with tetraplegia may also receive care from paid caregivers who are not nurses or otherwise formally trained in how to care for someone with tetraplegia. In order for people with tetraplegia to get the best possible care at home (rather than having to stay in a hospital or nursing home) it is important that they be able to tell someone when they need care and what needs to be done to help them (referred to as “direction of care”). It is also important that family members or others who are providing care to someone with tetraplegia learn how to properly perform these care tasks.

The process of learning to direct and provide care usually begins in acute inpatient rehabilitation. Clinicians and other rehabilitation professionals provide instruction about SCI and its consequences as well as hands-on training in directing care and providing assistance in tasks such as bowel and bladder care, transfers, bathing, range-of-motion exercises, and other activities. Ideally, people with tetraplegia and their caregivers are offered opportunities to practice directing and providing care, and receive feedback from rehabilitation professionals on their performance. Learning direction of care and caregiving skills continues after discharge as people with tetraplegia and their families continue rehabilitation in an outpatient setting and gain experience in the community.

While training in direction of care and caregiving is an important part of inpatient rehabilitation, current assessment tools and outcome measures provide no information on these skills. Commonly-used tools such as the Functional Independence Measure provide scores that are based on the level of independence of the person with tetraplegia. For skills that pertain to physical activity, such as transfers, these tools do not differentiate individuals who are actively engaged and in control of the task via verbal direction from those that are not participating in any way. Similarly, the quality of the assistance provided by the caregiver is not considered in the scoring of these tools. As a result, the rehabilitation field does not have a systematic (well-defined and consistent) way of describing how well someone can direct or provide care.

3. Anticipated Benefits of Using the TEAM Tool

The TEAM Tool is expected to enhance rehabilitation care by:

- Helping to identify training goals
- Documenting improvements in direction of care and caregiving skills over time, to provide justification for ongoing rehabilitation and to build confidence among those being trained
- Promoting conversations about difficult subjects such as care needs, willingness and ability of loved ones to provide care, interpersonal dynamics, etc.
- Facilitating discharge planning by helping clinicians assess and discuss readiness for discharge, identify areas in need of further training to prepare for discharge, etc.

The TEAM Tool is expected to enhance program evaluation and research by:

- Demonstrating the extent to which training programs improve direction of care and caregiving skills
- Facilitating assessment of relationships between direction of care/caregiving ability and important outcomes (such as complications, rehospitalizations, cost of care, and well-being)

4. Key Terms

Care director typically refers to the person with tetraplegia who is being trained to verbally instruct others in how to provide assistance. In cases where a person with tetraplegia is not being trained to direct care due to severe cognitive impairments or other issues, a family member or other responsible party may be trained to direct other caregivers (such as hired aides). In such cases, the responsible party is considered the care director.

Caregiver refers to a person who is being trained to provide assistance to the person with tetraplegia. The term “caregiver” is used in a broad sense, and may refer to paid or unpaid caregivers, including family members, friends, or staff that is hired privately or provided through an agency.

Team refers to the care director and caregiver working together as a unit. Because the dynamics between specific people are unique, each combination of care director and caregiver is its own “team.”

Trainer refers to a clinician, rehabilitation professional, or other “expert” (such as an experienced peer educator) who provides training in direction of care and caregiving skills in a rehabilitation context.

Task refers to an activity or (more commonly) a set of activities related to a particular objective (such as proper body positioning) or area of functioning (such as eating and drinking). Each person with tetraplegia has a unique combination of needs and preferences. Therefore, the specific tasks to be performed will vary from person to person. Other forms of documentation, such as the medical record or checklists for caregivers, can provide detail on the specific tasks to be performed for a particular person with tetraplegia. The types of activities included in each task (the “scope” of the task) is defined in Section 6 below.

Scale refers to a way of “measuring” a particular aspect of care direction and/or caregiving performance. The TEAM Tool includes three scales: *Safety*, *Problem-Solving*, and *Communication*. Because these scales represent distinct concepts, scores are calculated separately for each scale using different scoring criteria.

Domain refers to a collection of tasks that relate to a larger goal or activity. The TEAM Tool provides information on six domains: Preventing Complications, Mobility in Daily Life, Other Activities, Communicating Effectively, Home and Community Living, and Managing Personnel.

Domain Score refers to a score that is calculated within a particular domain, based on scores for all applicable tasks within that domain. Domain Scores are calculated separately for the Safety, Problem-Solving, and Communication scales.

Overall Score is calculated for each part (A, B, C) of the TEAM tool based on *all* the scores recorded for the tasks listed within a particular part (A, B, or C) of the form. Overall scores are calculated separately for the Safety, Problem-Solving, and Communication scales.

5. Structure of the TEAM Tool

Listing of Tasks

The TEAM Tool consists of three parts, organized by the nature of the tasks included in each part.

- **Part A** focuses on tasks that are fundamental to health and/or everyday functioning for which direction of care/caregiving training typically begins in an inpatient setting.
- **Part B** addresses communication-related behaviors that are observed by trainers as people with tetraplegia and their caregivers practice direction of care or providing care during training.
- **Part C** addresses more advanced skills related to maintaining one’s home, participating in community activities, and managing hired staff (if applicable). The tasks in Part C are included because they are considered important to people with tetraplegia and are needed for success in community life on the long-term. However, depending on the care setting, these areas may not be addressed in inpatient rehabilitation. Training may occur in outpatient rehabilitation in the context of other programs offered post-discharge. These advanced skills are therefore placed in a separate section of the TEAM Tool, but may be scored by inpatient trainers if they are addressed in training.

Separate Scoring for Care Director, Caregiver, and Team

Within each part of the TEAM Tool, scores are given separately for the care director, caregiver, and for the team (care director and caregiver working together). This approach to score assignment is designed to reflect that the success of a caregiving experience involves contributions from both members of the care team, who may differ in their levels of ability. This approach also provides flexibility, allowing the TEAM Tool to be utilized with the person with tetraplegia who is receiving training even if the caregiver has not yet been identified or is unable to attend training.

6. Scope of Tasks

For all domains, an “other” field is available on the form to provide trainers the option of adding another task that is relevant to the person with tetraplegia but is not already listed.

Part A

Domain 1. Preventing Complications

1. Using Ventilator Properly. Includes ability to keep ventilator fully powered, properly maintained, and functioning at the correct settings as well as implementing emergency measures in case of a ventilator failure (including using manual bagging to maintain breathing and contacting appropriate people for help). May include use of supplemental oxygen if prescribed.
2. Keeping Airways Clear. Includes suctioning, assisted coughs, tracheostomy care, adherence to swallowing-related precautions, and other measures taken to prevent secretions or food/liquids from interfering with breathing.”
3. Managing Blood Pressure. Includes any actions taken to prevent a problematic drop or increase in blood pressure. Such actions may include use of stockings, abdominal binders, or other aids to help maintain pressure; medications to manage blood pressure; care with position changes to avoid sudden drop in blood pressure, and other actions.
4. Responding to Autonomic Dysreflexia. Includes recognizing signs of autonomic dysreflexia, taking actions to stop the dysreflexia (sitting up, emptying bladder, loosening clothing, using medication, etc.), and seeking emergency assistance if needed.
5. Maintaining Healthy Skin. Includes appropriate cleaning/rinsing of skin via a shower or bed bath, thoroughly drying the skin, applying lotion, handling the skin gently to avoid irritation or damage, and other actions needed to ensure skin remains clean, dry, and free of injury. Also includes inspecting skin in a manner that would allow signs of skin damage to be seen (such as using appropriate lighting, looking at all areas at risk), identifying areas that suggest a problem may be developing (such as pressure injury), and identifying appropriate actions to take to respond to what is found during inspection (adjusting sitting time or frequency of repositioning, contacting physician, etc.).
6. Emptying Bowels Regularly. Includes implementation of the prescribed bowel program. This includes use of medications or supplements, enemas or mini-enemas, suppositories, stimulation with one’s finger or a device, and other actions required so that all stool is removed from the bowel. Also includes correct assessment of when bowels are empty and performance of bowel emptying techniques with appropriate hand hygiene/glove use, and in a manner that reduces the likelihood of

injuring the anus, rectum, or other bowel structures. May include proper colostomy use if applicable. Also includes ability to identify when a bowel problem may require further intervention by a physician or other health care professional.

7. Emptying Bladder Regularly. Includes implementation of all actions required to ensure that the bladder is emptied completely and regularly. Includes proper hand hygiene, glove use, cleansing of skin in the areas where bladder emptying is occurring, and handling of supplies to prevent infection. Also includes correct use of bladder medications, catheters, physical techniques to induce urination (such as applying pressure), as prescribed. Also includes ability to identify when intervention by a physician or other health care professional may be required to address a possible infection or other issue (as indicated by the amount, odor, color, cloudiness of urine).
8. Using Medications as Prescribed. Pertains to taking medications at appropriate times and dosages, including ability to identify potential side effects and take action to follow-up on medication-related issues.
9. Proper Body Positioning. Includes static positioning in bed and wheelchair. May include supporting shoulders to avoid dislocation, preserving tightness in hands when needed for grasping objects (tenodesis), positioning body to avoid excessive pressure, ensuring ability to reach bed or chair controls independently (if applicable), using splints or other devices to help hold the body in the correct position, and other actions required to keep the person with tetraplegia's body in a position that prevents complications (including pain, skin damage, range of motion problems, falls) and maximizes their ability to function.
10. Shifting Weight Regularly. Includes all aspects of directing or performing weight-shifting in bed or wheelchair, including performance on an appropriate schedule, correct duration of shift, correct use of technology to assist with shifting (such as controls for tilting), use of an appropriate variety of shifting techniques, and performing shifts in a manner that would avoid acute or chronic injury to the person with tetraplegia or his/her caregiver.
11. Performing Range of Motion. Includes performance of exercises to prevent loss of motion in arms, legs, hands, or other body parts. Technique of moving and monitoring for signs of problems (such as grimacing, increase spasticity, etc.) may be considered in scoring.

Domain 2. Mobility in Daily Life

12. Transfers Between Surfaces. Includes all aspects of directing/performing transfers between surfaces that are level or uneven (except for floor to chair transfers or other transfers intended for emergency use). Includes transfers to and from bed, wheelchair, commode/shower chair, and car. Includes appropriate use of equipment, appropriate set-up of the surfaces involved in the transfer, receiving/providing assistance as needed to perform the transfer and avoid a fall, etc.
13. Emergency Transfers. Pertains to transfers that may be needed in case of emergency, such as getting up from the floor or getting out of the chair quickly in case of malfunction or emergency requiring evacuation outside of the chair.
14. Moving Around in Bed. Includes receiving/providing appropriate assistance to move from sitting to supine (laying), rolling, scooting, etc.

15. Moving Around by Wheelchair. Includes directing/providing appropriate assistance to move via wheelchair over level or uneven surfaces such as floors, ramps, and grass. Also includes using doors, elevators, and wheelchair lifts. Excludes curbs or stairs. When scoring, consider guarding techniques, cueing or assistance for maneuvers in tight spaces, and ability to use manual mode if needed for power chair users. Mark this task Not Applicable if the person with tetraplegia will walk as their primary mode of mobility, and use the “Other” task in this section to rate direction of care and assistance provided in relation to walking.
16. Managing Wheelchair Parts. Includes manipulating parts of the wheelchair to allow for transfers, wheeling or driving the chair, storage or transport of the chair. Includes moving and positioning armrests, footrests, headrest, drive control, or other parts. For manual wheelchair users, includes removing and replacing wheels and folding the chair (if applicable). For power wheelchair users, includes charging the chair but excludes driving it into a vehicle (which would be considered part of Walking or Wheeling on Uneven Surfaces above).

Domain 3. Other Activities

17. Eating and Drinking. Includes directing a caregiver and/or providing assistance in bringing food and drink to the mouth. Excludes cooking and food selection. Includes positioning the person with tetraplegia appropriately (to prevent food going into the airway, enable him/her to hold/reach utensils, cups, etc.), providing food in appropriate bite sizes and at an appropriate rate, etc.
18. Bathing. Includes directing a caregiver or providing assistance in washing body and hair via shower, bed bath, or other means. Excludes transfers involved in bathing, which are covered under either Transfers Between Level Surfaces or Transfers Between Uneven Surfaces depending on the setup.
19. Grooming. Includes washing face and hands, brushing and flossing of teeth, shaving, styling hair and (if applicable) applying makeup in the manner preferred by the person receiving assistance.
20. Dressing. Includes dressing of the upper and lower body in a manner that avoids complications (as might occur from clothing or shoes that are too tight) and achieves the appearance desired by the person receiving assistance.
21. Phone and Computer Access. Includes directing/providing assistance with use of a telephone (land-line or cellular), tablet, laptop computer, desktop computer, or other electronic device used for communication, information access, control of environment, or other purposes. *Note: This task may overlap with others that involve phone or computer use, such as Work, School, or Leisure Activities. Behaviors that relate both to phone/computer use and to the performance of another task may be considered in the scoring of both tasks.*
22. Maintaining Stock of Supplies. Includes directing/providing assistance with inventory of medical and household supplies, ordering, and organization of supplies once received.
23. Maintaining Equipment. Includes directing/providing assistance with inspecting equipment (wheelchairs, cushions, shower chair, commode, mattress, etc.) for signs of wear and tear or malfunction, cleaning equipment (to maintain its appearance and/or function), making arrangements for routine checks or repairs by technicians when appropriate.

Part B**Domain 4. Communicating Effectively**

24. Using Appropriate Words and Tone of Voice. Includes addressing the other member of the care team (care director or caregiver) using their preferred title or name, expressing gratitude, avoiding negative words or insults. Also includes speaking at a volume and pace that is conducive to understanding, using a tone that is appropriate to the situation. Also includes non-verbal aspects of communication, such as eye contact, smiling (when appropriate), avoiding negative gestures or actions (sighs, groans, eye-rolling, etc.).
25. Acknowledging Concerns. Includes ability to recognize when there is a concern, misunderstanding, or other issue and speaking up about it before a problem occurs. Signs of misunderstanding may include hesitation in speaking or performing a task, or actions or gestures (such as furrowed brow, sighs, groans, frown, unusual silence, etc.). Appropriate acknowledgements of the concern might include asking the other member of the team if he/she has a question about what is being done, stopping the action to point out something that needs to be done differently, asking the other member of the team if additional or different instructions would be helpful, etc.
26. Rephrasing or Changing Instructions When Needed. Includes ability to use different words or other techniques (such as demonstration--when feasible, reference to a document, picture, or video, etc.) to help the other member of the care team understand what is being said or requested.
27. Providing Helpful Feedback. Includes telling the other member of the care team what worked well and what did not in the care interaction, using language that is respectful and non-accusatory in tone.
28. Being an Active Listener. Includes behaviors such as making eye contact, allowing the speaker to speak without interruptions (except when needed to clarify what is being said), restating what was said to make sure it was understood, etc.

Part C**Domain 5. Home and Community Living**

29. Child Care. Includes directing/providing assistance with addressing the child's basic needs (bathing, food, clothing, diapering, toileting) as well as participating in activities together (games, homework, etc.).
30. Pet Care. Includes directing/providing assistance with addressing the pet's basic needs (feeding, taking care of waste, cleaning/grooming, other aspects of maintaining the health and well-being of a pet), as well as participating in activities together.
31. Maintaining a Clean and Healthy Home Environment. Includes assistance related to house cleaning as well as laundry.
32. Food Preparation. Includes assistance with shopping, meal planning, cooking, storage/packaging of food, etc.

- 33. Managing Legal/Financial Documents and Affairs. Includes directing/providing assistance with handling of mail, bills, banking, and other affairs.
- 34. Transportation and Travel Planning. Includes directing/providing assistance with packing appropriate supplies, verifying accessibility of transportation and lodging, managing time to ensure on-time arrival, etc.
- 35. Work, School, or Leisure Activities. Includes directing/providing assistance with activities specifically related to taking classes, performing job functions, participating in recreational activities, etc.
- 36. Performing Exercises for Strength or Fitness. Includes proper performance of recommended home exercises such as functional electrical stimulation cycling, strengthening exercises, etc.
- 37. Facilitating Intimate Relationships. Includes working with a caregiver to prepare for sexual activities, including appropriate positioning, adjustment of catheters or other equipment, contraceptive use, etc.

Domain 6. Managing Personnel

Note: Tasks in this section apply only to those who be using the services of hired caregivers. Only the care director's performance is scored in this section.

- 38. Recruiting and Interviewing. Includes advertising for help, scheduling interviews, conducting interviews.
- 39. Establishing Expectations and Policies. Includes describing care needs, setting rules of conduct, etc.
- 40. Coordinating Coverage and Schedules. Includes setting schedule for caregivers and communicating that to others as needed; identifying backup plan in case of staff illness or other issue.
- 41. Transitioning to New Staff as Needed. Includes communicating intent to terminate work relationship, preparation of documents, etc.

7. Scoring Criteria

Scores are given for care directors, caregivers, and the care team for three different scales: Safety, Problem-Solving (Parts A and C only), and Communication (Part B only). These scales reflect different aspects of direction of care or caregiving performance. The scores for each scale reflect the extent to which the care director, caregiver, or team are able to appropriately execute that aspect of task performance without assistance from the trainer. Assistance may include physical help, cueing or reminders given via words or gestures, responding to questions asked by the care director or caregiver, or other forms of help. Descriptions of each scale and their scoring criteria are given below:

Safety Scale: Addresses ability to direct or perform a care task in a manner that prevents illness or injury (physical, emotional, or financial) to the person receiving assistance or his/her caregiver.

Safety Scoring: How much of the care direction/caregiving is performed safely *without assistance* from the trainer?

1. None – Requires assistance from the trainer to direct or perform all of this task safely
2. Some – Able to direct or perform *some* of this task safely without assistance from trainer
3. Most – Able to direct or perform *most* of this task safely without assistance from trainer
4. All – Able to direct or perform *all* of this task safely without assistance from the trainer

Problem-Solving Scale: Relates to the ability to adjust how a task is directed or performed in response to unusual or challenging circumstances to maintain safety and/or increase efficiency.

Problem-Solving Scoring: How much of the problem-solving process can be done *without assistance* from the trainer?

1. None – Requires complete assistance from trainer to identify problems and implement solutions
2. Some – Able to identify problems, requires assistance from trainer to identify and implement solutions
3. Most – Able to identify both problems and appropriate solutions but requires assistance from trainer to implement solutions
4. All – Able to identify problems and appropriate solutions, and can implement solutions without assistance from trainer

Communication Scale: Relates to the ability of the care director and caregiver to communicate effectively and appropriately with one another.

Communication Scoring: How much of the time is communication occurring effectively *without assistance* from the trainer?

1. None – Unable to communicate effectively without assistance from trainer
2. Some – Able to communicate effectively *some* of the time without assistance from trainer
3. Most – Able to communicate effectively *most* of the time without assistance from trainer
4. All – Able to communicate effectively *all* of the time without assistance from trainer

Note that “None” and “All” should be interpreted as “nearly none” and “nearly all.” A score of “None” may still be given if a task is done without help but only on rare occasions. Similarly, a score of “All” may

still be given if occasional errors are made but are self-corrected (therefore not requiring assistance) or if assistance is needed on rare occasions or when there are very unusual circumstances.

There is not a strict percentage associated with “some” or “most”—we leave it to the judgment of the trainer to determine which score best characterizes the ability of the care director, caregiver and or team being scored.

8. General Principles for Completing the TEAM Tool

Scores are based on observations of care director and caregiver behavior made by the trainer(s) during training. The TEAM Tool is designed to be completed by rehabilitation professionals (or other “trainers” as defined above) based on observations that they make during the process of training people with tetraplegia to direct their care and training family members or others to perform care tasks (such as assisting with a transfer or catheterization). Scores should be based on behaviors observed during practice of direction of care or caregiving whenever possible, to the extent that practice of these tasks occurs in typical clinical care.

For those tasks that are not feasible to practice in clinical care (such as responding to autonomic dysreflexia) an assessment may be made via a discussion of how the person with tetraplegia would direct the task or how his/her caregiver would perform the task. (It is anticipated that most of the tasks in Part C, which involves community skills and personnel management, will need to be assessed in this manner.)

It is not necessary for the person with tetraplegia AND his/her caregiver to be present for an assessment to take place—in the event that a caregiver is not present or available, a rehabilitation staff member may serve as the caregiver, with direction of care provided by the person with tetraplegia.

Scores are only given for tasks that *involve the assistance of a caregiver*. The TEAM Tool is designed to provide information about direction of care and caregiving ability. Any task that the person with tetraplegia is able to do on his/her own (or is being trained to do on his/her own) should not be scored.

For example, a person with tetraplegia may be trained to drive a power wheelchair over flat surfaces. If the goal of training is for the person with tetraplegia to be able to perform this task without any assistance (supervision, cueing or physical assistance) from a caregiver, then this task should be marked “Not applicable” and should not be scored in the TEAM Tool.

If however, the expectation is that the person with tetraplegia will utilize supervision, cueing, or other assistance from a caregiver for power wheelchair driving over level surfaces post-discharge, this task should be scored.

No changes in typical clinical care are required for the TEAM Tool to be completed. The TEAM Tool is intended to assist the process of training people with tetraplegia and their caregiver by encouraging evaluation of these skills by the rehabilitation team, and providing a mechanism for documenting and communicating assessment findings. The TEAM Tool may “inspire” changes to the training process by drawing attention to areas in which training is needed, but changes in typical care are NOT required for the team tool to be completed.

Decisions about what skills to train, how to train them and when to provide training should be driven by clinical considerations and not by the need to complete the tool. Clinicians may choose to incorporate

the tool in their training efforts in whatever ways feel most appropriate, including reviewing it with patients/caregivers during training, discussing with other members of the patient's clinical team, etc.

Any trainer may score performance in any task that he/she observes. While the scope of practice differs among clinical disciplines (occupational therapy, physical therapy, nursing, etc.), there is often overlap between disciplines in the topics of training. For example, both nurses and occupational therapists may provide education related to intermittent catheterization. For purposes of pilot-testing, any trainer may score any task that is considered part of his/her training activities, regardless of his/her clinical discipline. *(Note: These instructions may be changed in future pilot-testing to have scoring divided among clinical team members.)*

Scores are based on observations made during a one week look back period. Scores given on the TEAM Tool are based on observations of behavior made in the week prior to (and including) the date the trainer is completing the tool. A look back period of this length is provided to maximize opportunities to observe various skills, since it is rarely feasible to observe all skills in a single day or even over 2-3 days. It also gives trainers flexibility to complete the tool when their schedules permit.

Scores should be given based on the trainer's assessment of the CURRENT abilities of the care director or caregiver. For tasks that are performed multiple times during the look back period, performance may vary over the course of the week. The trainer should pick the score that he/she feels best reflects the abilities of the care director or caregiver as of the date the TEAM Tool is being completed.

For example, in a situation where performance improved over the course of the week, and less help was needed from the trainer, the score given on the TEAM Tool should be based on the more recent observations.

In other situations, performance may be inconsistent, such that lot of help from the trainer is needed on some days and little on others, with no discernable trend of improvement. In such a case, it may be more appropriate to give a score that reflects the poorer performance, even if little help was needed at the most recent observation. If inconsistency of performance is related to task setup (an "idealized" setup vs. one closer to that of the home environment) scoring should be based on the setup that is closest to that of the home environment.

Trainers should assign scores based on the perceived need for assistance, even if assistance was not actually provided. There may be circumstances in which assistance may be needed but is not actually given. For example, a care director and caregiver may be communicating inappropriately early in the training process but the trainer has not yet developed the rapport necessary to intervene productively. In such situations, the trainer should assign a score based on the assistance he/she would have provided if circumstances permitted.

The TEAM Tool is designed to be completed at multiple points in time. The TEAM Tool is designed to be used at multiple time-points so that changes in skill level can be documented over time. The tool may be completed as often as deemed appropriate by the trainer(s). For purposes of pilot testing, the target windows for completion of the tool are:

- Within two weeks of admission to inpatient rehabilitation (Note: This instruction may be changed in future pilot-testing based on feedback indicating that it may be most productive to review the tool's content in this window, but defer initial scoring until later.)

- Near the midpoint of the inpatient rehabilitation stay (the middle two weeks of the stay, based on the best available information about anticipated discharge date)
- Within two weeks prior to discharge

If completion of the tool within these windows is not feasible, the research team will consult with trainers to identify appropriate timeframes.

9. Step-By-Step Instructions for Pilot-Testing of the TEAM Tool

1. **Select a day** within the target window to complete the TEAM Tool and obtain a TEAM Tool form. (Research staff will notify you of the window dates and will provide copies of the forms.)
2. **Fill out the date and ID fields** on the first page (research staff can fill in the remaining pages for you, unless you prefer to label them yourself).
 - ☐ Enter your clinician ID. IDs will be provided by the research staff.
 - ☐ Write the assessment date, which is the date on which you are completing the assessment form. All scores should be entered on the same day, based on observations made during care director and caregiver training during the week prior to (and including) the date on which you are completing the form. This period is referred to as the **look back period**.
 - ☐ Write the ID of the person with tetraplegia who is being trained. IDs will be provided by the research staff.
 - ☐ If a caregiver was trained during the look back period, enter the ID for that caregiver (also provided by research staff). Only one pairing of care director and caregiver should be assessed on a single TEAM Tool form. If more than one caregiver was trained during the look back period, enter the ID for the person who is most likely to be the primary caregiver and base your scores on the performance of this care director-caregiver team. (You may complete additional TEAM Tool forms for other caregivers if you wish, but this is optional.) If no caregiver was trained during this week, and you served the role of the caregiver during direction of care training, leave the caregiver ID blank.
3. **Complete scores for the tasks presented in Parts A and B.** For each task:
 - ☐ Determine if the task applies to the person with tetraplegia. Mark the task “NA” (not applicable) if:
 - It is not medically or functionally relevant to the person with tetraplegia (such as “Managing Wheelchair Parts” for someone who not a wheelchair user)
 - It does not require the assistance of a caregiver [such as “Mobility (Walking or Wheelchair) on Flat Surfaces” in the case of a person with tetraplegia who is being trained to be independent in power wheelchair mobility]
 - ☐ If the task is applicable, assign scale scores (Safety and Problem-Solving for Part A, Communication for Part B) as follows:
 - Use the scoring criteria on the bottom of page 2 of the TEAM Tool (and also described in this manual on page 13 to guide your scores.
 - Enter scores in the columns relevant to those who received training in the task during the look back period:
 - Blue column only: Only the care director (person with tetraplegia) received training

- Blue and yellow columns: Care director and caregiver received training, but did not practice performing a task together
 - Blue, yellow, and green columns: If both a care director and caregiver were trained and they practiced one or more tasks in that area together
 - A formal assessment is not necessary to enter a score of 1 (None) in any column—if the person (or team) being assessed has not received training or has not yet been asked to demonstrate any tasks within that area, enter a score of 1, indicating that they are not yet able to do any tasks in the task without assistance.
 - Leave a task blank only if it falls outside the scope of your practice (meaning that you do not provide any training relevant to this area and do not have expertise required to evaluate the performance.) If you wish, you may enter a dash in the box rather than leaving it blank. *(Note: These instructions may be changed in future pilot-testing if scoring is divided among clinical team members.)* Note that while inter-personal issues are often addressed by a psychologist, the tasks in the domain of Communicating Effectively are considered to be within the scope of all disciplines.
- ☐ If there is another task in a domain that is relevant to the person with tetraplegia but is not addressed in other tasks (such as wound care), write this task on the line marked “_____ (Other)” and assign scores as discussed above.
4. **(Optional) Complete scores for the tasks presented in Part C.** The tasks in Part C are considered more advanced or otherwise may fall outside the scope of what is typically covered in inpatient rehabilitation, therefore this section is optional. It is included in recognition of the importance of these skills for long-term success in the community and to prepare for later piloting of the tool in settings beyond inpatient rehabilitation. If you choose to complete Part C, please follow the instructions listed in item 3 above for Parts A and B. *(Note: These instructions may change in future pilot-testing that involves use of the tool beyond inpatient rehabilitation.)*
5. **Calculate Domain Scores.** *(If pressed for time, you may leave this to research staff to complete for you.)* Domain scores are calculated for each of the six domains: (Preventing Complications, Mobility in Daily Life, Personal Health and Appearance, Communicating Effectively, Home and Community Skills, Personnel Management Skills). Within each of these six domains, calculate domain scores for each column as follows:

$$\text{Domain score} = X \div Y$$

Where: X = Sum of the scores given to the tasks within the domain
(Enter this in the first blank of the “__ ÷ __” in the column)

Y= Number of tasks scored (not marked N/A or left blank) in the domain
(Enter this in the second blank in the “__ ÷ __” in the column)

If no scores appear in a particular column, leave the Domain Score lines blank.

6. **Calculate Overall Scores for Parts A, B, and C.** (You may leave this to research staff to complete for you.) Within each Part, calculate overall scores for each column as follows:

$$\text{Overall score} = P \div Q$$

Where: P = Sum of the scores given to the tasks within the Part
(Do not include the Domain Scores you calculated, only the scores for the tasks themselves. Enter in the first blank of the “__ ÷ __” in the Overall Score row.)

Q = Number of tasks scored in that Part
(Enter in the second blank in the “__ ÷ __”)

If no scores appear in a particular Part, leave the Overall Score lines blank.

7. **Note feedback on your experiences using the tool.** Space is provided on page 4 of the TEAM Tool packet for you to share comments about difficulties with scoring, tasks that were not included, uncertainties in the instructions, etc. The purpose of pilot-testing is to identify what works well and what does not, so all feedback is welcome.
8. **Return form to designated location for collection by the research team.** A member of the research team will collect the forms on a regular basis.

9. Resources on Care Direction and Caregiving
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<u>Title/Description</u>	<u>Accessible/Downloadable From</u>
A Step-by-Step Guide to Training and Managing Personal Assistants: Consumer Guide)	http://familyserviceswe.ca/sites/default/files/documents/a%20step-by-step%20guide%20to%20training.pdf
How to Successfully Hire and Manage a Personal Care Assistant: For People with Spinal Cord Injury (also available as iBook)	http://www.sfphysio.fr//docs/2015131740_how-to-successfully-hire-and-manage-a-personal-care-assistant-for-people-with-spinal-cord-injury.pdf
Managing Personal Assistants: A Consumer Guide (PVA)	http://www.pva.org/atf/cf/%7BCA2A0FFB-6859-4BC1-BC96-6B57F57F0391%7D/persasstfc6d.pdf
Personal Care Assistance: How Much Help Should I Hire	https://craighospital.org/resources/personal-care-assistance-how-much-help-should-i-hire
Personal Care Assistants: How to Find, Hire, & Keep	https://craighospital.org/resources/personal-care-assistants-how-to-find-hire-keep
Long Term Caregivers: For Better and For Worse	https://craighospital.org/resources/long-term-caregivers-for-better-and-for-worse
As the Years Go By: Accepting New Help	https://craighospital.org/resources/as-the-years-go-by-accepting-new-help
Video: Perspectives From Those Providing Care	http://sci.washington.edu/care_providers/index.asp
Video: Managing Personal Caregivers: A Panel Discussion	http://sci.washington.edu/caregivers/index.asp
Video: Personal Caregivers: Tips, Tricks and Tales from Individuals with Spinal Cord Injury	http://sci.washington.edu/info/forums/reports/caregivers.asp
SCI Forum Report – Personal Care Attendants	http://sci.washington.edu/info/forums/reports/attendant.s.asp
The Rough Guide to Managing Personal Assistants	http://www.independentliving.org/docs6/vasey2000.html
Caring for Caregivers – SCI InfoSheet	http://www.spinalcord.org/resource-center/askus/index.php?pg=kb.page&id=299
Long Term Caregivers: For Better and For Worse	https://craighospital.org/resources/long-term-caregivers-for-better-and-for-worse
Hiring In-Home Help – Family Caregiver Alliance	https://www.caregiver.org/hiring-home-help